

关 注



Free copy

Guanzhu internal policy newsletter of AAIC facilitating exchange of ideas and sharing of experience within the organisation and between AAIC and its partners.

issue one, may-july 2004

Welcome

Welcome to the launch issue of *Guanzhu*, an internal policy newsletter by ActionAid International China (AAIC) linking people and policy. *Guanzhu* in Chinese means to care about an issue, to focus on it and to try to understand it better. With each issue of our newsletter we aim to *guanzhu* a specific theme. Our newsletter has two goals. First, as AAIC is a relatively young organisation the publication will help us enhance our understanding of each theme and formulate AAIC's position on it. Second, the newsletter will serve to share views and approaches among AAIC staff, with other ActionAid International (AAI) country programmes and with AAIC's partner organisations in China, including poor and marginalised people, the Government, Chinese Community Based Organisations (CBOs) and Non-government Organisations (NGOs), international NGOs and donors, as well as academia and research institutions.

In each issue you will find an overall analysis of a situation on a given theme in China, opinions of government officials and decision makers, voices of people affected by a given problem, opinions of social workers, AAIC's action and/or planned actions to address the issue in question, as well as a review of AAI's experience, approaches and lessons learned.

The first issue of our newsletter focuses on the fight against the AIDS epidemic, which is among the priorities of AAI. AAI has been working with HIV/AIDS since 1987 and approaches AIDS in a holistic way, paying attention not only to health issues, but to the wider context of people's social conditions, rights and empowerment.

We welcome all suggestions and constructive criticism of the newsletter. Please send your comments to mail@actionaidchina.org.

We share a similar fate, so we have to support each other, a self-help group run by HIV positive people is working to make a difference in their community.

In its work worldwide, AAI supports the Greater Involvement of People Living with or Affected by HIV (GIPA) rule that was first enshrined at the Paris AIDS Summit in 1994. AAI's experience proves that people living with HIV AIDS and communities affected by AIDS can greatly contribute to the effective response to the epidemic. AAIC talked to Mr. Dong, himself living with HIV, who is a member of a self-help group in one of AIDS villages in Henan province to learn about one model of involvement of PLWHA in response to AIDS in China.

continued page 7



Elderly woman and her granddaughter, whose parents died of AIDS

©Loving Source

At a critical point

The HIV/AIDS epidemic in China shows no signs of abating. On the contrary, it is growing at an alarming rate of more than 30% per year. Official estimates put the number of cases of HIV/AIDS in China at 840,000. The epidemic is spread unevenly, with low general prevalence but high concentration in specific regions among certain population groups. Furthermore, only 10% of people infected are aware that they carry the virus.

Alarmingly, sexual transmission infections are on the rise, meaning the disease is spreading to the general population. *The epidemic is at a critical point of spreading from high-risk groups to common people*, warned Vice-Premier Wu Yi at a national HIV/AIDS control conference in Beijing in April 2004. *We can completely contain the momentum if we take it seriously. Otherwise, we will lose this best, fleeting opportunity. The consequences will be quite serious*, said Vice-Premier Wu.

According to estimates, an unchecked spread of AIDS in China will create an epidemic of 10 to 20 million infected people by 2010 with accompanying disastrous social and economic consequences in the affected regions and populations. According to this negative scenario, the number of AIDS orphans will reach at least 260,000 children.

Stepping up of response by the central government

The Chinese government has promulgated a medium and long-term

strategy (China National Medium- and Long- Term Plan for AIDS Prevention and Control, 1998-2010), and an action plan (China Plan of Action to Contain and Control HIV/AIDS, 2001-2005) to prevent and control HIV/AIDS. In the last year the central government has intensified its response to AIDS through a series of actions. Conferences and other public events attended by government officials have been organised in Beijing and importance of responding to HIV AIDS has been emphasized by high level officials. The government has also sought foreign financial and technical support for the fight against AIDS.

In an important gesture of solidarity, Premier Wen Jiabao and Vice-Premier Wu Yi talked and shook hands with AIDS patients on December 1st 2003. New body, State Council AIDS Prevention and Control Committee, dedicated to improving coordination among government bodies was subsequently created in February 2004. The participating members include representatives of ministries, government agencies, mass organisations and seven provinces working under the guidance of Vice-Premier Wu Yi.

Under the *four free and one care* commitment the government has pledged to provide free anti-retroviral (ARV) treatment to rural residents with HIV/AIDS and to urban residents with HIV/AIDS who cannot afford it, free voluntary HIV tests and consultations, free schooling for AIDS orphans and free preventive treatment for

contents

Editorial..... 1

Review

At a critical point..... 2

People at risk and vulnerable groups..... 5

AAIC's position on HIV/AIDS..... 6

Grassroots voice

We share a similar fate, HIV positive self-help group.....1

Lessons learned

Examples of AAI's HIV/AIDS work..... 10

This publication may be used in any form. Please feel free to quote, translate, distribute and transmit. Please acknowledge the source.

mother to child transmission.

The China CARES programme, launched in 2003, focuses on community-based HIV treatment, care and prevention and provides free ARV treatment. This programme aims to cover 56 affected counties within the seven central provinces of Anhui, Hebei, Henan, Hubei, Shanxi, Shaanxi and Shandong. The government has received support for China CARES from the Global Fund to Fight HIV/AIDS, Malaria and Tuberculosis and is working on this programme in cooperation with NGOs and other agencies.

Key challenges to addressing AIDS epidemics - a development perspective

In spite of recent positive developments many challenges still remain if the HIV epidemic in China is to be halted and reversed. From a development and social perspective the main issues that AAIC considers key challenges to addressing the AIDS epidemic in China are as follows.

■ Need to strengthen political will and knowledge about AIDS at the local level

Even though the central government recognises AIDS as a serious challenge to public health, local governments at provincial and county level often play down the spread of AIDS in their locality. Officials are afraid that revealing the crisis will scare away investors and tourists as well as damage their political career. Recently, a clear signal was sent from Beijing that no cover-ups will be tolerated. *It (AIDS) must be reported faithfully. And anyone who intends to hide the epidemic should take responsibility and will be severely punished,* Health Minister and Vice-Premier Wu Yi told a conference on HIV/AIDS in April 2004.

Experts have pointed to the fact that local response to AIDS is key to effectively halting and reversing the epidemic. In China the awareness of the looming epidemic is still disturbingly low among local officials. According to a practitioner who often discusses AIDS issues with local cadres, the view *why should we care, if someone has HIV*

it is his/her own fault is quite common among local government leaders.

Knowledge about HIV/AIDS should also be enhanced among cadres. Based on one study, 59% of government officials could not correctly identify the ways in which HIV is transmitted. At the local level meagre funding for the fight against AIDS and a lack of effective coordination mechanisms are also major factors hampering the official response to AIDS.

■ Lack of access to primary health services in rural areas

Unless the issue of access to basic health services is addressed the prevention work among the general population and AIDS care and treatment in affected areas will be severely constrained. Rural areas, with 70% of the country's population, have less than 30% of the medical resources. Because of this lack of access to health services sexually transmitted diseases are spreading in rural China, increasing the risk of HIV infection. Poor quality of health services renders AIDS care and treatment ineffective. Doctors and public health workers working in rural areas affected by HIV/AIDS have no knowledge or training on ARV treatments. In this environment, the wrong treatments are administered and the possible side-effects are not fully communicated to the HIV positive people. As a consequence patients discontinue treatment due to side-effects, what can have disastrous impact on their health as well as cause the development of

drug resistant HIV strains.

■ Stigmatisation

In a similar way to other countries, high-risk activities such as commercial sex or injecting drugs is condemned as immoral, and people who engage in them are shunned by society. *There is still a lot of work for us to be done, so that it is understood that protecting human life is the most important thing, more important than protecting morality,* said an AIDS educator who works with sex workers.

However, the widespread public sympathy that met the Henan epidemic among former plasma donors is symptomatic of a general attitude that does not regard HIV-infected former plasma donors as immoral people who have inflicted the disease on themselves, as is often thought of sex workers, homosexuals or injecting drug users.

To make matters worse, as commercial sex and drug-taking are illegal, high-risk groups are often reluctant to come forward, out of fear of both moral and legal retribution. Also, many AIDS education activities for high-risk groups are conducted in detention and re-education facilities, where the atmosphere of control and condemnation makes them ineffective. Furthermore, even outside of such environments, the culture of silence that exists surrounding high-risk behaviour exacerbates the challenges of educating youth on how they should protect themselves.

continued, page 4

■ Discrimination of people living with HIV/AIDS (PLWHA)

Many HIV carriers and people affected by AIDS are subject to severe examples of discrimination. AIDS orphans are ousted from their homes and denied their right to study. PLWHA are denied medical health care by doctors afraid of becoming infected and there are reports of medical experiments being conducted on PLWHA in breach of regulations. In employment matters, it is enough for people to be known to come from the AIDS affected area to be denied work. There are also reports of PLWHA who are unable to support themselves as nobody buys their agricultural produce at the local markets because the producers are known to carry the HIV virus.

Forceful messages should be sent to the general public to dispel the fear that surrounds AIDS and to protect the rights of PLWHA and people affected by HIV/AIDS. Few localities have passed laws protect-

ing the rights of PLWHA, and in some places laws remain discriminatory towards PLWHA. In order for people to be willing to take tests and for PLWHA to come forward, they must be assured that the law will protect their rights such as residence rights, employment rights, education rights, marriage rights as well as right to privacy.

There is a great role for the media to play in reducing the fear among the public by promoting knowledge about AIDS and presenting positive examples of the lives of people living with HIV.

■ Links between AIDS and poverty

Poverty both causes and compounds the AIDS problem. Poor people are more likely to engage in risky behaviour like sex work or selling plasma and the poor generally have little education and little power in social interactions to help protect themselves from risks. For an effective response to the epidemic AIDS education and preven-

tion needs to be mainstreamed into development projects. Attention must be paid to ensure that poor people are given knowledge on AIDS transmission routes, and also that an environment is created that enables and empowers them to make safe and responsible choices and to act to reduce the spread of HIV.

About 70% of the people infected with HIV in China are living in poverty-stricken areas. When a person in family is found to be HIV positive or develops AIDS, the costs of treatment and the loss of labour and income has serious impact on the economic situation of the whole household, especially the children and the elderly. There is anecdotal evidence from AIDS villages that farmers are unwilling to take an HIV test, out of fear that, should they prove to be infected, they will have to cover the costs of the therapy.

■ Very limited involvement of civil society in response to AIDS

It was only very recently that the contributions made by a few Chinese NGOs and social workers in the fight against AIDS have been officially recognised. However, many social workers taking the side of people living with HIV/AIDS still face detention and investigation in the localities where they work. Also, local CBOs and individuals working to stop AIDS are often hampered by low capacity, lack of funding and lack of networking opportunities at the grassroots level.

Experience in other countries has demonstrated that the effectiveness of the response depends

selected references

China Ministry of Health and Un Theme Group on HIV/AIDS, Joint Assessment of HIV/AIDS Prevention, Treatment and Care in China, December 2003

Futures, Attitudes towards HIV/AIDS in China: Research on public knowledge, attitudes and behaviour in cities and towns, 09 2002

Kaufman Joan and Jing Jun, China and AIDS, The Time to Act in Now, Science, 28 June 2002

Pilcher Helen. R. Married homosexual men could make sex significant route of transmission in China, 20 June 2003,

South China Morning Post, Survey Exposes Deadly Ignorance of Sex Workers, 09. 20.03

www.moh.gov.cn

www.china-aids.org

www.chain.net.cn

in no small part on the meaningful involvement of many different groups in the AIDS response programmes. The combined efforts of people living with and affected by HIV/AIDS, and relevant CBOs and NGOs, create truly participatory approaches in AIDS projects known to build local responsibility, reduce stigma and discrimination, address conflict in communities, enhance mechanisms for communication and create feedback between the people and the government.

This need for an increased involvement of NGOs and CBOs in AIDS prevention and care work in China has been recently acknowledged by the central government. A senior official at the Ministry of Health recently declared, *China is forming a new AIDS prevention and control mechanism, in which non-governmental organisations will play an important role.*

Indeed, in China, NGO workers are better placed to work with high-risk groups like sex workers or drug users than are government workers, as the activities in which these high-risk groups engage are illegal.

However, what is still needed in order to mobilise the NGOs are coordination mechanisms, and more financial and technical support to strengthen the work of local NGOs and CBOs engaged in the areas where NGOs have the strength to fight against AIDS.

People at risk and groups affected by AIDS

In China there are several AIDS epidemics, and vulnerable groups differ significantly from place to place.

Injecting drug users

According to government data, of the total number of reported HIV infections, 64% were caused by sharing needles among intravenous drug users. In 2002 there were one million registered drug users, an 11% increase on the preceding year. Half of the number were injecting drug users, and one quarter of the number shared needles. HIV cases among injecting drug users have been found in all provinces, regions and municipalities in China. However, primary concentrations are found in Yunnan, Xinjiang, with HIV prevalence reaching up to 80% among drug injecting populations and in Sichan, Guangxi and Guizhou, where 50%, 43% and 34% respectively of injecting drug users were reported to be HIV positive in certain areas.

Ethnic minorities

Ethnic minorities are especially vulnerable to HIV infection. While they make up only 8% of China's population, they account for more than 30% of reported HIV/AIDS cases. This has been attributed to high occurrence of drug use among ethnic minorities.

Sex workers and their clients

The WHO estimates that there are 6 million sex workers in China. Sex workers and their clients are in-

creasingly vulnerable to HIV infection. Already in 2000, 10% of sex workers in Guangxi and 4.2% in Yunnan tested positive for HIV. At the end of 2002 the proportion of sexually transmitted HIV infections was reported to stand at 10.9%, a substantial rise from 5.5% in 1997. Without appropriate action to address high risk behaviour, the sex industry could become a powerful vehicle for the transmission of the HIV virus to the general population. As a national study in 2000 indicated, the main clients of sex workers are middle-class men below 35 years old.

Awareness of the need for condom use among both workers and clients is very low. According to WHO studies, fewer than 20% of sex workers use condoms regularly. Another study has found that two in five of the sex workers covered by the survey had never had a health check, and more than half did not consult doctors when they contracted STDs. Fewer than one in five sex workers practiced safe sex with their husbands or boyfriends. A parallel survey found that clients said they would pay more for unprotected sex, and about 40% said they had sex without a condom.

Former plasma donors

In central China unsafe plasma donations in the 1990s have caused an extremely high prevalence of HIV infections among farmers. In some villages the incidence of HIV infections is more than 60%. Now, with full-blown AIDS developing in many HIV positive people there, a

humanitarian crisis compounded by poverty is rapidly unfolding. Government data states that around 9.3% of all reported HIV infections were among the paid plasma donors. However, experts and activists put the estimated number of people infected through plasma sale much higher, with some suggesting that there are 1 million people infected through this mode of transmission in Henan alone.

Although Henan is the most prominent example of a province affected by AIDS caused by commercial plasma donations, others include Anhui, Shanxi, Shaanxi, Hebei, Hubei and Guizhou. These provinces have also reported cases of HIV acquired in this way and some communities are experiencing similar localised epidemics. It is unclear how many of the communities affected have been acknowledged by the government and how many of them are receiving any aid.

Despite the introduction of strict laws and regulations on blood management and a crackdown on the illegal blood trade, there are still occasional reports of unsafe blood collection practices.

Men who have sex with men

There are estimated to be between 2 and 8 million gay men in China. In recent surveys of gay men in Beijing half the men reported having had unprotected sex with men in the previous six months and almost a quarter said they had had unprotected sex with women during the same period.

The results of the survey also suggest that Chinese gay men are afraid of being stigmatised by homosexual behaviour, and in addition to homosexual

relationships they maintain a heterosexual relationship.

There are fears that married men who have been infected by other men could be spreading the infection to their wives. Ten percent of gay men in China reported regular use of condoms with their homosexual partners or spouses. One study forecasts that in 2010, more than 15% of HIV positive people will have become infected through unsafe gay sex.

Migrants

China's migrant population is estimated at 100 to 150 million people, mostly at a sexually active age. There are fears that temporary migrants could be more likely to visit sex workers than non-migrants, as they are away from their families and spouses. Migrants could thus act as a *bridge population*, bringing the HIV virus from the cities to places in the countryside where it has been previously unknown.

Rural women

In rural China reproductive tract infections are widespread among rural women. This is mostly due to the poor state of health care services in the countryside. Diagnosis is poor, there is little respect for patients' confidentiality and medicines for sexually transmitted diseases are expensive. Having a reproductive tract infection increases the risk of HIV infection. An AAC survey in 2003 has found the general awareness of the existence of AIDS to be high among village women in Hebei. However, the women had little knowledge of the specific channels of transmission of the virus.

AAC's position on HIV/AIDS

The overall mission of AAC in its HIV/AIDS focus is to work with poor and marginalised communities to control vulnerability, achieve sustained improvements in the quality of life and facilitate the realisation of rights in the face of HIV/AIDS, by working through local, national and international partnerships. AAC is in the process of developing its HIV/AIDS programme. Its work will be guided by the following objectives:

- To centrally involve PLWHA and people affected by HIV in AIDS response.
- To bring the voices and opinions of people living with HIV/AIDS to the attention of the general public and decision makers.
- To promote networking for grassroots organisations and individuals committed to the fight against AIDS.
- To mainstream HIV/AIDS education and prevention in all our projects, with a special emphasis on bringing AIDS knowledge to rural women.

We share a similar fate, *continued from page one*

The idea of setting up a self-help group was born out of Mr. Dong's experience. *In 1998- he says, the health of my wife deteriorated. We went from one doctor to another but nobody could tell us what was wrong with her health. We spent all our money and got in debt. Finally, at the hospital in province capital the doctor told my wife to take an HIV test. Then we discovered we were both HIV positive. I started collecting all available information about HIV AIDS. At that time more and more people started to have problems with health. I didn't want other people to go through our experience and get in debt trying to find out what was wrong with their health, so if I knew they had symptoms of HIV infection, then I told them they should go and get tested straight away.* Four years later the self-support group works in ten administrative villages inhabited by 50,000 people, among whom 500 people are officially registered as HIV positive.

The village Mr. Dong comes from is one of so-called AIDS villages. It is located at the outskirts of county seat town and composed of four big administrative villages and numerous natural villages with an

Self-help group in which Mr. Dong participates is divided into seven working groups

Education group, aiming to educate the people so that the discrimination of PLWHA is reduced.

Mediation group, aiming to solve conflicts among PLWHA and between PLWHA and the government.

Deathbed care group, providing a simple care training for families of people living with HIV and AIDS.

Drug's side effects group aiming to collect the information about treatment and its side effects and share them with the government.

Children's group aiming to collect information about the living conditions of children in affected families and sharing it with the government.

School project group providing HIV and AIDS education in local elementary schools.

Management group responsible for the planning and evaluation of the work of other groups.

overall population of 36,000 people. Only 5000 inhabitants are registered as farmers (have agricultural hukou). The list of people living with HIV AIDS that hangs on the wall of the village clinic has 104 names on it. However, as not everyone has taken the HIV test, the real number is probably higher. Most of PLWHA are poor farmers. *People with non-agricultural hukou usually have permanent jobs, so they didn't sell blood. There isn't much land in my village. Even before HIV started spreading the income of farmers in our village was lower than that of an average farmer in the region. At that time people were able to feed themselves with their own produce. Now, due to disease, they have limited ability to work and many survive on the flour distributed by the government.*

The beginnings

Farmers in Mr. Dong's village sold blood in early nineties. In year 1997 some people began to show symptoms of HIV infections. *In 2000 there was already a rumor around that people who sold blood are infected with HIV virus, but nobody really knew anything about the disease.* Mr. Dong started to collect and analyze all available information on HIV AIDS he could find and share them with fellow villagers. *I learned a lot myself by reading relevant materials and books. If there were things I didn't understand I contacted doctors from Beijing hospital, who specialize in AIDS and whom I have come to know.* In 2002 Mr. Dong started to bring the HIV positive villagers to Beijing hospitals, so that they can get proper, usually free, medical advice. Since then he has helped more than 300 PLWHA in this way. Mr. Dong has also organized a small resource center in his village, where PLWHA can find books, magazines and VCDs containing information relevant to HIV AIDS.

Besides access to information, medical advice and treatment, another issue that needed addressing was lack of knowledge of AIDS among general population and severe discrimination of PLWHA. *In the first years after people started to show symptoms, the situation of people who have tested positive was very difficult. People who were known to be HIV positive, didn't even go out of their houses. Nobody would buy their produce. People wouldn't even hold the*

banknotes that PLWHA had touched. It was extremely difficult to live with HIV back then. Now the situation has improved slightly, as people slowly get used to the presence of people living with HIV AIDS and partly because of my group's education work. However there is still much discrimination. For example, in some

schools children from affected families are asked to sit at the back of the class and teachers never ask them anything.

Mr. Dong believes that the main reason behind discrimination is lack of knowledge about AIDS among unaffected people. He illustrates the scope of the ig-

Community led analysis of the living conditions of PLWHA and of the side-effects of ARV treatment

There were several reasons why the self-help group decided to conduct the comprehensive analysis of the living conditions of PLWHA and of the side-effects of ARV treatment that they are receiving. First, the self-help group observed that the government is providing free ARV drugs, but it is often not used in the proper way. Detailed and specific information from the research could prevent the waste of the state's resource as well as the loss of PLWHA's opportunity to benefit from the treatment. Second, the analysis aimed at finding out what information PLWHA needed and at providing it to them. Third, it meant to provide first hand information to the government on the living conditions of PLWHA and people affected by AIDS. The main fields of inquiry were: health status of PLWHA in the village, ARV treatment that they receive and its side-effects, the level of knowledge about possible side effects among PLWHA, the knowledge about opportunistic infections, situation of children in the affected families, and other family members, condition of the housing of HIV positive people.

The analysis was done meticulously and took two months to complete. Each household interviewed was visited several times. Attention was paid so that the answers are true and correct. Children were interviewed in a relaxed environment in order to obtain a true and full account of their situation. While the self-support group members were collecting information, they answered the interviewees questions related to ARV treatment, its side effects, and treatment of opportunistic infections. A doctor from one of Beijing's hospitals visited the village during the time of research to help group members deal with medical questions. The results of the analysis were shared with the local government.

Among the main findings of the analysis were the following

- Out of 94 qualified respondents only 19 persons were taking the medicine properly; 39 persons were taking medicine improperly (with improper timing, cutting down the quantity of medicine or mixing three kinds of medicine at will), 20 persons stopped taking medicine midway, 16 persons didn't receive medicine or didn't take it even though they had received it.
- With a few exceptions, people who took the medicine properly had good results.
- Loss of labour due to side-effects was among the reasons cited for stopping the treatment.
- Many respondents lacked knowledge about the possible side effects of the treatment that they were provided.
- Many respondents lacked knowledge about the treatment of opportunistic infections.
- Children from affected families are discriminated against in schools
- Families of PLWHA lack basic knowledge of how to care for AIDS patients
- Majority of people living with HIV expressed will to work on enhancing the quality of their lives.

norance problem with a story. At the beginning of this year there was a man, who after learning that he was HIV positive first closed himself for three days in his house, and then committed suicide by drowning himself in the nearby lake. After his death nobody wanted to eat fish from the lake. People either burned or buried all the fish they caught. This led me to think of how much there is still to be done to educate people about AIDS.

Current work and challenges

Mr. Dong's work has gradually attracted other people living with HIV. We share a similar fate, so we have to support each other- he says. Now the self-support group, which relies on volunteer work, has seven full time members and 15 supporting members, who are divided into seven working groups (see box 1). Recently the self-support group has conducted a comprehensive research among 104 HIV positive people in their village in order to collect various information on their lives and to share these with the government (see box 2). Mr. Dong believes that his group has the capacity to conduct all the work, because of the systems and work rules that they have set up. *For example -he explains, the person responsible for the school project has to take a note of how many schools he has visited, how many classes he has organized, what was the attitude of the teachers, how did the students react to his presentation, etc. This information is passed to the management group that provides monitoring and keeps track of this person's workload.* The self-support group receives technical advice from AIDS social workers and some financial support from one of Chinese NGOs.

Mr. Dong believes that the biggest challenge his group is facing is financial in nature. *The biggest problem we have now is that people who have worked with us for a long time, quit, because if they continue to work with us then they have no means to provide for their families-*says Mr. Dong. He receives 100 RMB per month for his almost full-time work.

We don't want to be famous

While in the past the group was under strict supervision by the local government, which hampered their

work, in the last year the situation has changed. The group has lately received praise from the provincial level government for their AIDS work. Members were invited by the provincial government to participate in meetings relevant to AIDS. The county level government has also recognized the work of their self-support group. Mr. Dong has become a party member. The self-support group also cooperates with the village committees in ten administrative villages that they work in. The village committees help them organize village meetings, let them use their facilities like village committee's office or a loudspeaker, as well as provide evaluation and financial supervision of the group's work.

Asked what advice he has for other similar self-help groups Mr. Dong says: *The advice I can give is to learn by doing and develop your work gradually. Also, it is quite important to stay low key. That is to say, it is OK to involve the media for the sake of the PLWHA, but if you work with the media just to promote yourself, then it might influence your relations with the government. We don't work with media because we want to really achieve something without being famous.*

This text is based on an interview with Mr. Dong and on personal communication with social workers who work with PLWHA in Henan province. Because AAIC's interviewee wished to remain anonymous a pseudonym was used in this text.



Children from one of AIDS villages

Examples of ActionAid's International HIV/AIDS work

■ Stepping Stones

The Stepping Stones training package promotes social change and gender equity as a way to improve sexual and reproductive health. A series of community-based workshops develop individual decision-making and communication skills, improve relationships between men and women, and create a supportive environment for sexual and reproductive well-being. Stepping Stones was created in sub-Saharan Africa from 1993 to 1995 in response to the HIV/AIDS epidemic, but it works from a broad gender and human rights perspective. Therefore, it addresses a wide variety of issues, ranging from gender-based violence to alcohol abuse to sharing household finances.

The Stepping Stones process begins by meeting with community leaders to explain the program and invite their support; these leaders then invite community members to participate. The workshops follow a fission-fusion model: peer groups (older women, older men, younger women, and younger men) meet separately to discuss their varying experiences and perspectives, but periodically come together in joint plenary sessions to exchange views and find common ground.

The original Stepping Stones manual includes 18 three-hour workshops held over a period of three or four months, covering four themes: group cooperation, HIV and safe sex, why we behave the way we do, and ways in which we can change. All of the workshops employ participatory, non-formal learning, and the discussions, role plays, and drawing exercises do not require participants to be literate. During workshops, participants analyze local issues based on their own experiences and develop locally appropriate solutions. At the program's end, the peer groups come together, perform dramas illustrating key lessons, and make formal *requests for change* to the entire community. In Uganda, for example, one such request was for older men to stop waiting outside schools to pick up girls and take them to bars.

Evaluations, both formal and informal, of Stepping Stones workshops in many countries have identified a variety of positive changes in attitudes and behavior, including:

- Greater knowledge of reproductive health issues.
- Enhanced decision making and communication skills that, for example, enable women to refuse unwanted sex and men to resist peer pressure.
- Mutual respect, dialogue, and improved relationships between partners and between generations; for example, men may share domestic chores more often, while parents may talk openly about sexuality with their children.
- Reduced alcohol consumption and gender-based violence.
- Greater prevalence of safer sex practices, including abstinence, condom use, fewer sexual partners, and less extra-marital sex.
- More equitable sharing of household resources.
- Less stigma and discrimination directed toward people living with HIV/AIDS and their caregivers.

Many organizations have translated and modified the Stepping Stones manual for use in other countries, mostly in Africa and Asia but also in Russia and Latin America. They have developed new modules to address local priorities, including reproductive rights, gender violence, teenage pregnancy, contraception, infertility, abortion, puberty, menopause, and sexual problems. To support the use of Stepping Stones by partners around the world, ActionAid International provides guidelines and advice on how to train people as facilitators and adapt the manual, shares information about users' experiences, and links organizations that are using Stepping Stones with one another.

Experience with Stepping Stones in a wide variety of settings has concluded:

- Dividing participants into peer groups by age and gender encourages them to speak freely and allows them to explore attitudes, behaviors, and vulnerabilities in a safe and comfortable environment.

- Working in separate peer groups ensures that Stepping Stones captures the varying perspectives, needs, concerns, and insights of different gender and age groups.
- The fission-fusion model encourages better and more assertive communication across sex and age lines, but it has the potential to create conflict between peer groups unless carefully managed.
- Communication between partners and between generations is more likely to improve if both partners or all family members participate in the workshops, but it may be difficult to persuade them to do so.
- Formally requesting the community to make changes creates a supportive environment and positive peer and community pressure for behavior change.
- Because the participatory approach makes participants feel valued and respected, it helps bring about behavior change
- A team of well-prepared and skilled facilitators (ideally two women and two men) is essential, but the program may need to recruit and train people to fill the positions.
- Sustaining change over time requires further meetings, facilitator and peer support, and continuing reflection and action.

■ Bag of love

Mahendra Nagar, the far western region of Nepal, is the core area from which many Nepalese migrant workers go to work in different parts of India. They are a significant high-risk group in terms of vulnerability to infection. ActionAid International Nepal supports the Nepal National Social Welfare Association (NNSWA) to address the issues of trafficking, HIV/AIDS and migration. NNSWA has introduced a unique program of sending Maya Ko Thaili (bag of love) to the Nepalese migrant workers working in different parts of India. This Thaili includes a letter from the family, some family memorials and HIV/AIDS related pamphlets and it aims to *arouse emotional feeling* in the person working abroad. The aim is that after getting the Thaili, the worker will think about his family and feel a sense of responsibility, which can make him aware of HIV/AIDS and the need to protect himself from unsafe sex.

■ Work with orphans in Kenya

Widows and orphans in Kenya continue to bear the brunt of HIV/AIDS related deaths of their husbands and fathers respectively. When this happens the relatives of the deceased take away all the family property leaving widows and orphans without any inheritance. AAIK works with CBOs and NGOs to empower widows, orphans and affected communities with legal information and paralegal skills to enable them stand up and fight for their rights and resist relatives who would otherwise disinherit them from their meager property left when their husbands and parents die. This activity causes a ripple effect and the people who go through paralegal trainings are able to identify violation of rights in the communities and refer the affected to the different support and legal structures within the communities.

Other activities the CBOs and NGOs undertake through AAIK funding include the Memory Project, which targets parents living with HIV/AIDS and guardians/foster parents of orphans and vulnerable children and empowers them to develop supportive strategies for the children. Specifically the parents are taught how to disclose their status to their children, write wills, discuss with the children the issues of property inheritance and document the family tree. The parents are also given skills on how to discuss difficult issues with their children such as permanent separation caused by death. Further the parents are encouraged to discuss HIV/AIDS with their children as they go through the Memory Project. Consequently, the project does not only give skills to the parents but also empowers the children with HIV/AIDS information and skills to stand up to stigma and discrimination that often face children of people infected with HIV/AIDS.



© ActionAid UK



© ActionAid UK

ActionAid International China
68 Xin Zhong Jie
8 Julong Garden, apt. 304
Dongcheng District
Beijing, 100027, China

mail@actionaidchina.org
www.actionaid.org/china



© ActionAid UK

AAIC team thanks Tom Burgess and Richard Deshoka who volunteered to proofread the texts for this issue.