

SUPPORT GROUPS BELONG TO THE COMMUNITY AND NOT TO BHASO

One of BHASO's main objectives is to build capacities of people infected and affected by HIV and AIDS for positive living. Support groups are the cornerstone of the network of the people who are living with HIV.

By Farai Mahaso*

BATANAI HIV and AIDS Service Organisation (BHASO) is a registered local HIV and AIDS Service Organisation (PVO No 16/36) operating in Masvingo Province in 5 rural Districts and 1 urban District. It started as Batanai HIV and AIDS Support Group, a support group for people living with HIV that was formed by the late Auxillia Chimusoro in 1992. Auxillia Chimusoro was the first person in Zimbabwe to disclose her HIV-status to the general public of Zimbabwe. During those days the government and the people in the communities were still in denial mode and were not yet open up to the obvious presence of HIV and AIDS. She disclosed her HIV positive status and started Batanai support group because she wanted to give HIV a face. This was also an effort targeted at fighting stigma about HIV.

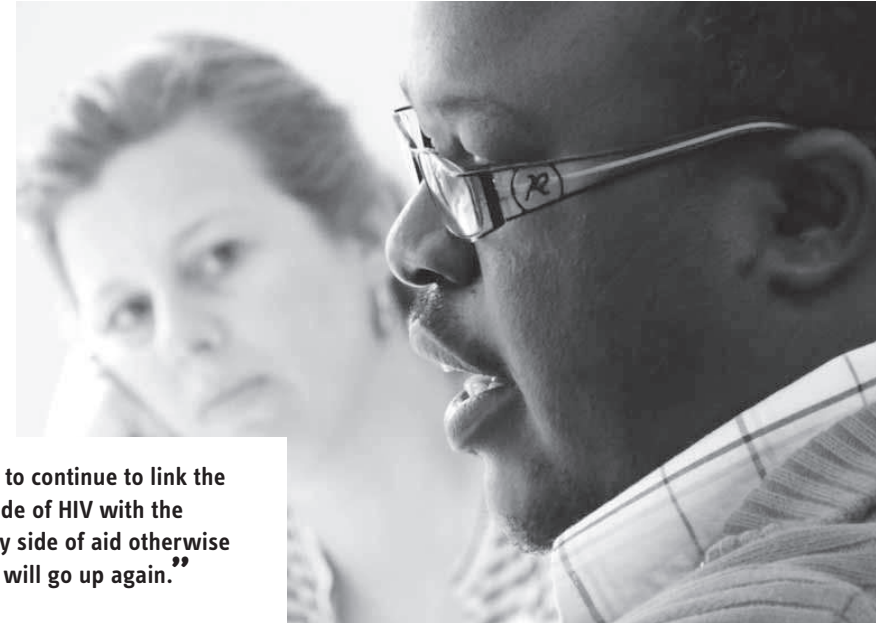
Auxillia Chimusoro helped to open doors for the government to be able to start to do something concrete towards addressing HIV and also for people living with HIV in her community to fight for support and for a place where they could meet and carry out their activities as a support group. Looking back at that time there were no ARVs and no treatment: Many people living with HIV were surviving with hope and gave each other support and advice on health, nutrition and social issues while hoping to live longer and positive lives.

I still remember when I started to work with HIV support groups, we were usually busy trying to register members for medical policies and to look for transport to take those who were seriously ill to their rural homes where they could die. Studies which have been done over the years show that people are surviving and live longer. So the vision of ending HIV is possible. We can see that in Africa. If we see someone who dies of AIDS, we feel that no one is supposed to die because there is an option for everyone to survive.

BHASO'S VISION IS: TOTAL EMPOWERMENT FOR POSITIVE LIVING

Auxillia believed in it and we also believe in the truth of that spirit. We want people living with HIV to fight and to be in the forefront of managing and ending HIV and AIDS respectively and because they understand their situation better and understand each other. However, they need skills; that is where we come in. That is our vision.

BHASO's Mission is to empower people infected by HIV and AIDS by providing services that will enable them to improve the quality of their lives. We facilitate empowerment; everything in the communities should be done by the people themselves after we have given them the skills. This way the whole process becomes sustainable.



“ We have to continue to link the medical side of HIV with the community side of aid otherwise infections will go up again.”

If we look at the evidenced based programming that we do, the issue of ownership and making sure that people themselves understand everything we can see that the concept is working well. Zimbabwe has managed to reduce the HIV infection rate from around 20-30% to about 13.7% and this has happened mainly because of behaviour change. So we believe that if you invest in the people you will get results.

One of BHASO's main objectives is to build capacities of people infected and affected by HIV&AIDS for positive living. We train people because if you want to empower people you have to give them information and skills. You need to give them the opportunities to do something for themselves so that at least they are able to work for themselves. This is our approach and our recommendation.

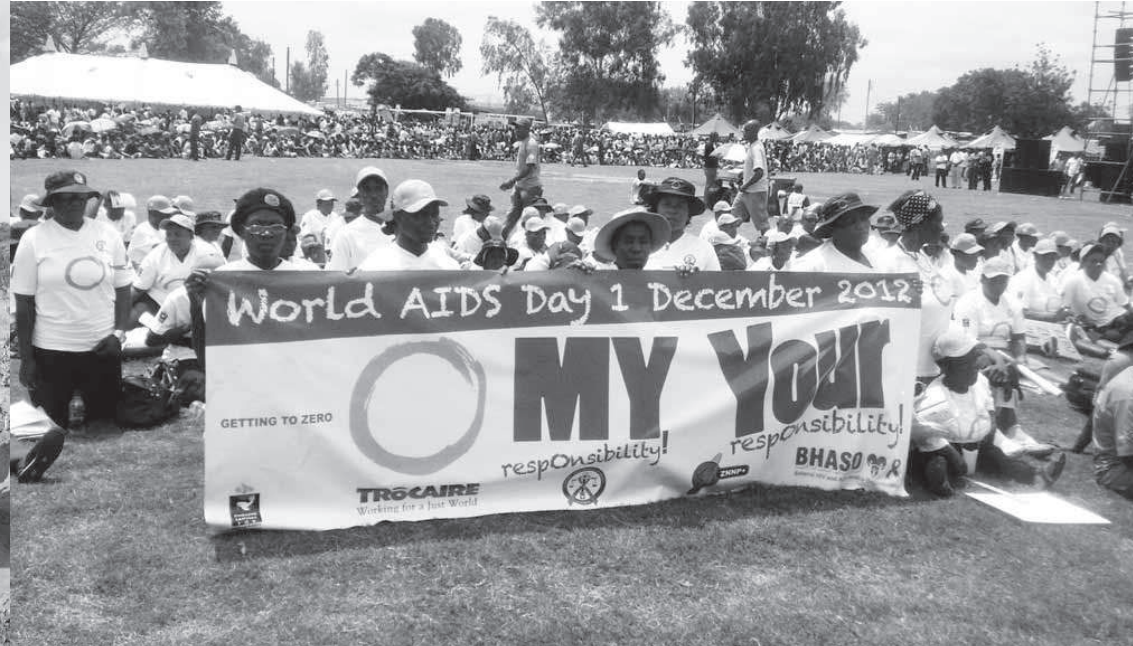
Some people ask me: “Why do you include food in your programming?” My response is: “I believe that people need to take food to get stronger and healthier and be able to take ARVs. We also believe, if the people are going to do all these things, it will help to shape their personality and their quality of life will be improved.

SUPPORT GROUPS

We are currently operating in eight districts of Masvingo Province. We realized over the years that the support groups are the cornerstone of the network of the people who are living with HIV. We work with about 700 HIV support groups.

These support groups help each other, they give each emotional support. Unlike other support groups in Africa they are open for everyone; people in the communities know where they meet. They give the people information and they also support people on the ground.

In terms of prevention and care, support group members support each other and also help each other to adhere to treatment. So in the end what we see is a community that is organized. We train them on leadership skills and on how to organise and run their groups and activities. Because of the support groups' visibility service providers coming into their communities are better positioned to direct resources where they are most needed. If a service provider comes with a program and tells them what to do, they are empowered enough to say this is how we want things done for our community. We are passing this way. We can prevent our brothers and sisters from getting HIV.



We developed a model of expert agents which we called Community HIV Support Agents (CHASA). This people are identified from the support groups as people who are living with HIV. They are supposed to be on treatment for a year or so. These people understand what is happening. We train them for ten days on treatment, they get all the important information and they volunteer to work for two days to work at the health centre.

This is very helpful and improving the work because when people living with HIV (PLHIV) are coming to the health centre they can see a face that they are familiar with and then they are able to talk about the ARVs. And also the health staff realized that there is now a greater engagement and that adherence is improving. This is because they know each other in the support groups.

The people within this network of PLHIV support each other and the adherence to medication is high. We realized that the people who are in the support groups survive more than the people who are not in the support groups. That is what we learned over the years.

MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV AT ALL LEVELS

BHASO targets people living with HIV at all levels of HIV. We help them to be able to raise their voice, to fight for their rights and becoming recognized. We have developed a concept and encouraged them to participate during its development. We have empowered them to participate in different committees put in place at clinics and hospitals. So if they are in there, they are able to influence what happens in the community and be influential enough to change unfavourable policies.

At BHASO we strongly believe in the promotion and protection of the rights of people living with HIV. We advocate from a human rights based approach. What is it that needs to be done to protect the rights of people with HIV? We were asking the government. We developed advocacy strategies that have community structures starting from a local ward level to a district, to a provincial and up to a national level. We have trained Advocacy Teams who in turn identify advocacy issues in their communities and advocate for them.

For example: We found that the ARVs were not arriving, that they are stored somewhere in Zimbabwe. It was found that the drugs were stored in the capital city and it would need some action to bring them to the province where they are needed. Advocacy teams investigated and found out that drugs were not ordered. Maybe there was someone who was not doing his job. So the people demonstrated in front of the Medical Provincial Director's office until the office agreed to look into the problem. This way the local level advocacy structures started to negotiate for their interests and their rights.

We try to implement our activities at low costs because we know that if people are empowered they know what is supposed to be done and they are organized enough to do it themselves. We realized that by the end of the day most of the work is done by the people themselves and as an organisation we then don't need to do much. People realize that by getting information and skills they can do things for themselves. Now we feel that people do understand what they are fighting for and what their rights are.

We also try to link people with the health system and to the continuum of care from the community – people in the community know what is happening. We have developed a concept whereby people living with HIV on ART volunteer to support each other when they come to collect their medication from the Health centres. They also follow up on those who may be defaulting.

NETWORKING AND BUILDING ALLIANCES

We realized that when doing advocacy and talking to ministers and other high ranking officials you need to be well prepared and equipped, especially when you want to change the laws. As an organization we started to network with the Zimbabwean Lawyers for Human Rights and also with the National Network for People living with HIV. We started networking with other organizations outside of Zimbabwe in order to get information at international levels. This way when we went and sat down with policy makers we realized that we can actually put our cases forward and be heard. We realized that we could do it, we could tell them what we want.

Working with relevant government ministries, community leaders and traditional leaders is another element of our strategy. We are supposed to adhere to the Zimbabwe National HIV & AIDS Strategic Plan (ZINASPII). This way we can make our plans comply with the national plans of our country. Our role is to take care of the needs of the communities. So we have to say the truth about what people need and follow up on what government says it will do. We have to align between the needs of the community and the policy of the government.

HOLDING GOVERNMENT TO ACCOUNT

BHASO does a lot of work holding government to account about the funds allocated for HIV work. The Zimbabwe government has put a tax that every employee and employer is charged to contribute towards the fight against HIV. Zimbabwe actually is one of the few countries in the world that has such a national fund on HIV. This means that we are not just waiting for donations from donors and if we are looking for funding from the Global Fund we are in a position to put down our own contribution. This best practice has been well documented. But when we looked at how the government allocates the money and whether it is used properly we discovered that a lot of money is going to administration – and this is not the right way to do it.

BHASO managed to discuss with the government officials asking them to ensure proper allocation and distribution of funds in a transparent way. We also requested the government to stop buying expensive drugs when cheaper varieties are available on the market. When the government didn't cooperate we engaged with the Zimbabwe Lawyers for Human Rights and presented our demands. We went to court

to file our complaint and demanded for information from the National AIDS Council. They still refused.

In Zimbabwe it is very difficult to organize a demonstration. We organized around one hundred people and arrived at the office of the National AIDS Council. People came from different directions with posters and slogans – it was impressive. It was captured by everyone. The people in the government and the National AIDS Council got nervous because the event was reported in the international media. Donors were asking what is happening. So it was a way to try to hold government to account.

After that demonstration we also continued to engage the national director of the National AIDS Council. We are doing this because we are tightening our demands. However we are not yet near the fundamental issues regarding what is supposed to be done. We are still communicating and so now they really understand if they are doing anything now there are people who are watching what is happening and what is going on. This is one concrete example that happened.

WE NEED TO CONTINUE OUR EFFORTS

We can't say that there is medication and we are reaching universal health coverage. No, HIV is still there. And if we don't continue our efforts, HIV infections are still going to increase. This is what people need to know.

We have to continue to link the medical side of HIV with the community side of aid otherwise infections will go up again. Some people say that it would be more convenient to buy ARVs. But our experience is that you just can't use ARVs alone without the community support.

We also need to increase more funding for HIV into the Global Fund to fight AIDS, Tuberculosis and Malaria. Some donor countries are pledging money to the Global Fund but are not paying. We need to make sure that they are paying. We also need to go to some of our governments to tell them that it is important to invest in the HIV response because we are saving lives.

We also need to encourage our governments to increase domestic funding because it is more sustainable. We are trying to tell them to admit to the Abuja commitment of 15% government funds to health, because health is a human right.

India

COMMUNITIES MAKE IT POSSIBLE

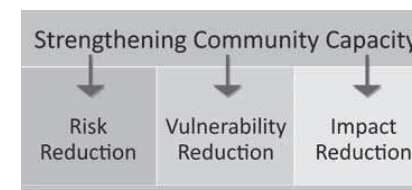
Empowerment and collectivization are the drivers of sustained risk reduction. If you want to go fast, go alone. If you want to go far, go together.

By Sanghamitra Iyengar*

SAMRAKSHA is an NGO working in North Karnataka, a developmentally deprived area in South India with poor development indices. It has been travelling with people vulnerable to, living with and affected by HIV for the past 20 years, learning, strategizing and changing. It strongly believes that individuals and communities have the capacity to deal with the issues they face including HIV/AIDS and that they need to be at the centre of any HIV response. It also believes that transformational change has to come from within.

Samraksha's work has focused on the Continuum of Prevention to Care, helping to strengthen the capacity of communities. It works with – populations of women in sex work, men who have sex with men, vulnerable youth, village communities and people living with and affected by HIV – to reduce risk, overcome vulnerability and to mitigate impact.

This paper will examine the concept of critical enablers proposed by the Investment Framework conceptualized by UNAIDS (Lancet, 2011) through Samraksha's experiences in HIV prevention work with women in sex work.



WOMEN IN SEX WORK

The women in sex work that Samraksha is associated with are predominantly from rural communities, largely from lower socioeconomic backgrounds with low literacy, living usually in the community with families. They are geographically dispersed.

Many of them have another occupation and sex work provides supplementary income. A majority of them enter sex work after marriage or a failed relationship. It is mostly economically driven, but it is a choice. The Pan India Survey (2013) of women in sex work revealed that 70% of sex workers in India choose sex work over other occupations. Ironically they report exploitation, abuse, sexual harassment and low pay and poor working conditions as the reason for crossing over from those occupations to sex work.

The context in which they operate is challenging. Largely, their sex work identity has not been disclosed to their family, children or neighbours. Where this identity has been openly disclosed, they report facing stigma and discrimination, harassment from the police, the neighbours and even the family. There is lack of dignity and social status. Where the identity is hidden, the vulnerability increases as they have to tolerate violence, exploitation and blackmail to keep their identity hidden. In such a situation, dealing with consequences of disclosure or prevention of disclosure takes priority over reducing HIV risk for oneself or others.

In this context, the cornerstones of HIV prevention, behaviour change communication,

* **FARAI MAHASO** is the Coordinator/ Director of BHASO, the Batanai HIV/AIDS Support Service Organisation, Masvingo, Zimbabwe. BHASO is supported by the Swiss NGO fepa (Fonds für Entwicklung und Partnerschaft in Afrika), a partner organisation of the aidsfocus.ch platform. Contact: farai mahaso fmahaso@bhaso.org, www.bhaso.org cationsdetails.aspx?id=90547