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Positive living

Introduction

The first wave of many national responses to HIV/AIDS tended to paint HIV/AIDS as a terrifying grim reaper of death knocking down innocent people in the way a bowling ball knocks over pins in an alley. Indeed, that was the first image shown on Australian TV about HIV/AIDS in the 1980s. The grim-reaper approach represented an attempt to grab people's attention and to knock down people's defence mechanisms—including denial—that could prevent them from changing their risky behaviour.

In many countries, denial was the first phase and was typified by comments like 'HIV/AIDS doesn't exist' and 'HIV/AIDS is a hoax to stop us from having fun'. The second phase was to acknowledge that HIV/AIDS exists but to see it as a foreign body—

carried, for example, by a tourist—that invades your own social body, your own society. The third phase to emerge was the view that HIV/AIDS is part of an unacceptable social body—deviants like commercial sex workers, homosexual men and injecting drug users. The fourth phase was to see HIV/AIDS as part of the normal, mainstream social body and to model, publicise and advocate the idea and reality of *positive living* for those with HIV/AIDS. The phrase people living with AIDS (PLWA) was designed to reverse the emphasis of first-wave *HIV/AIDS-is-death* messages to more positive messages that include the spirit of *Life goes on with HIV/AIDS, and let's all, together, make the most of it*.

These four phases mirror common historical patterns of the spread of HIV/AIDS in many countries

Toleration and discrimination in HIV/AIDS prevention and care

'Discrimination against people with HIV/AIDS or AIDS has more than morally and ethically unacceptable direct consequences. Systematic discrimination against people with HIV/AIDS jeopardises prevention and care efforts. This argument, the public health rationale for preventing discrimination, was developed at the international level by [the World Health Organisation] WHO. The argument gained a high profile in 1989, when people with HIV/AIDS were excluded from travelling to the USA and certain other countries. Activists around the world joined virtually all major HIV/AIDS and public health institutions in decrying these restrictions not only as a violation of human rights, but as a barrier to the improvement of programs through the free exchange of information at forums such as international AIDS conferences.

This second level of analysis is also reflected in the increasing arguments that the fear of human rights

violations undermines HIV/AIDS efforts by driving people at risk and people from affected communities underground, and away from prevention and care services.

The author of the above quote, J. O'Malley, went on to identify a third level of analysis that viewed discrimination against men who have sex with men and against other risk groups as being a causative factor in itself. This third level of analysis and linkage was supported by the UN Human Rights Committee in its landmark 1994 decision to decry discrimination against consensual homosexual actions among adults. In its decision, 'the UN Human Rights Committee considered that criminalising homosexuality would impede an effective education campaign regarding HIV/AIDS prevention'.

Textbox 5.1

O'Malley, J. (1996), 'Tolerance and Discrimination' in Mann, J. and Tarantola, D. (eds), *AIDS in the World II*, Oxford University Press, Oxford, p. 466-7.

as well as common historical psychological attitudes to HIV/AIDS and those living with it.¹ Societies, however, are complex and diverse. No society has travelled entirely to the fourth phase. So, punitive, discriminatory and violent attitudes to people living with AIDS still exist. Similarly, government and non-government staff who see PLWA as patients, or victims, or as part of infection control were and are still common.² These attitudes are closer to the spirit of accepting *positive living* for those with HIV/AIDS', but more progress is required.

Also important in this context is the third leadership commitment proposed in UNAIDS' recent global strategy framework: 'To reduce the stigma associated with HIV and AIDS and to protect human rights through personal and political advocacy and the promotion of policies that prevent discrimination and intolerance and enable more open discussion of sexuality as an important part of human life'.³

As pragmatic, compassionate policies and attitudes became more widely accepted as the international norm, HIV/AIDS best-practice principles began to discourage heavy-handed scare tactics to avoid driving PLWA further underground, away from HIV/AIDS education, counselling, treatment and care. The new approach also sought to avoid the risk of scaring people away from accepting (i) HIV/AIDS as a life risk that can be minimised and (ii) PLWA as ongoing, valued members of the social body.

Project contributions to positive living for PLWA

The main ways that projects contributed to promoting *positive living* with AIDS included:

- ❖ promoting factual information about HIV/AIDS transmission and prevention that may reduce fears and stigma associated with HIV/AIDS and PLWA—avoiding negative-living messages;
- ❖ promoting community care networks;
- ❖ facilitating PLWA associations and self-help groups;
- ❖ promoting PLWA positive and active

UNAIDS' public-health rationale for promoting positive living for PLWA

Prolonging the productive lives of individuals infected with HIV/AIDS increases their ability to contribute to the well-being of their families, also helping to decrease the discrimination and pauperisation which can make surviving family members more vulnerable to HIV. Similarly, increasing investments in education, care, social support and general development efforts within affected communities strengthens their capacity to respond to the epidemic.

These strategies contribute to creating an environment where human rights are realised, stigma reduced, and the frank discussions required to address AIDS can take place. A more supportive and open environment helps reduce the vulnerability of community members to HIV infection.

Textbox 5.2

UNAIDS, *The Global Strategy Framework on HIV/AIDS*, UNAIDS, Geneva, 2001, p. 11.

involvement in planning, managing, implementing, monitoring and evaluating HIV/AIDS responses;

- ❖ advocating on behalf of PLWA, although preferably promoting and supporting advocacy by PLWA;
- ❖ financial support to PLWA, their families and other primary health carers.

Positive messages

Prevention

As noted earlier, HIV/AIDS responses can promote or discourage *positive living* with HIV/AIDS through their prevention messages. The content of projects' prevention curriculum was not always researched or reported in detail in evaluation reports. In general, evaluation teams were supportive of the general direction of the education component. Only two evaluations were critical of the curriculum, reporting that projects used negative-living images in the prevention campaign.

In facilitating community learning about how HIV/AIDS is spread and not spread, probably all HIV/AIDS projects promoted *positive living* for PLWA. As people learn over time that HIV/AIDS is not

spread by touch, sharing food, sharing public toilets, kissing and so on, more people are likely to be confident that they can buy food, eat, touch and socialise with PLWA with minimal risk of infection.

The Danang II evaluation team presented evidence that the project had made a positive contribution to the *positive living* of PLWA and to members of high-risk groups through their promotion of a pragmatic, harm-reduction approach to government staff:

Tensions have continued between objectives of the [government's] punitive social evils campaign, under which commercial sex workers (CSWs) and injecting drug users (IDUs) can be arrested and their behaviour

publicly stigmatised, and harm reduction approaches to HIV/AIDS prevention, which depend for success on communication and trust. The evaluation found evidence of an evolution towards growing acceptance of harm reduction. This may be attributed partly to the project (through seminars about research findings; study tours for project staff; frequent meetings between partners). Some problems clearly remain; particularly alarming is learning that IDUs may have contracted HIV/AIDS after their incarceration in a re-education camp lacking clean needles and syringes.⁴

Probably the prevention campaigns of most projects in the second half of the 1990s focused more on

Connection between prevention, care and positive living for PLWA

Similarly it seems surprising that there was no scope within the Mumbai project design for support and care of those infected with and affected by HIV. Certainly the epidemic has increased exponentially during the three years of the project, but HIV already had a hold in Mumbai at the time the study was planned and it could easily have been predicted that there would be demand for such support, counselling and care from the project. The links between care and prevention of HIV have been well conceptualised and documented from experience in other parts of the world. It seems a shame that local project staff are learning about these links from first principles towards the end of the project when this could have been an integral component from the outset.

Ordinary people tend to be aware that infectious diseases spread through coughing, sneezing, touching, and sharing food and dishes. It is counter-intuitive that a fatal infection might not spread in these ways. So a great deal of reassurance needs to be given about the ways that HIV does not spread to reduce the fear that is such an important underlay of stigma. Demonstrating care and support to HIV infected people is one of the most powerful and effective ways that workers can provide this reassurance to families and other community members, thus breaking down discrimination. Project staff told an important story which illustrates this point well.

The mother of a young man who was ill with HIV had spent a lot of money on medicines that had not worked—but when she discovered that her son had AIDS the family lifted the ill boy on his bedding and

left him by the side of the road. No one would touch him. Project staff came and helped the boy, and took him to hospital, where he was treated and made a good recovery over time. Meanwhile the project staff talked with his family and gave them information about how HIV does and does not spread, and encouraged the family to accept their son back into the family. Because of this counselling the family completely changed their attitude and welcomed their son back. The family were very grateful to the project staff for their intervention.

This is a very important story. It demonstrates how successfully attitudes can be changed, and shows the connection between care and prevention. When families are reassured about how HIV does not spread, and see others touching people with HIV then they are willing to accept infected people—and others are also then more likely to accept positive people without discrimination. When people see that they will not be discriminated against they are more likely to be willing to come forward for testing, counselling and treatment, and to make efforts to ensure that they do not transmit the infection to others. It becomes possible for them to lead productive positive lives. Also local families see that neighbours are affected by HIV, so that they believe that it is possible for them to become infected too, and they are then interested to learn how the virus spreads so that they can protect themselves.

In a setting such as this prevention efforts that begin with care and support are thus more likely to be effective and less likely to increase stigmatisation than attempts to change behaviour through the IEC approaches adopted in this project.

Textbox 5.3

Mumbai Evaluation Report (1999), p. 25-26.

fidelity, abstinence and condom use than on the demonic or deathlike figures sometimes used in countries like Australia and Thailand in the early 1990s to capture community attention.⁵

Community-wide and high-risk-group focus

One way that projects can contribute to *positive living* is to take a community-wide focus on high-risk behaviours rather more than on high-risk groups. A danger of a special focus on high-risk groups, especially stigmatised ones such as commercial sex workers (CSWs), injecting drug users and men-who-have-sex-with-men, is that community members may identify HIV/AIDS and PLWA as primarily associated with one of these groups, pushing PLWA further underground to avoid the additional stigmatisation.

The Songkhla 1 evaluation team made a related point when it noted there were ‘perceptions in the communities that CSWs are to blame for the epidemic’ and recommended that the project help develop ‘new and specific IEC messages stressing that HIV/AIDS is a societal problem, and that all segments of society should join in combating the epidemic’.⁶ The evaluation report did not indicate who or what led to community perceptions, but suggested that the project had a role in helping to change community perceptions of blame.

Prevention messages focusing on marginalised risk groups such as commercial sex workers as a cause of HIV/AIDS can lead to PLWA being seen as CSWs or their clients. This form of stereotyping is not conducive to a climate where PLWA can live positively with self-respect and community respect. It can also lead to the message that men should only use condoms with CSWs. ‘Perhaps the most important gap in knowledge’, notes the Songkhla I evaluation team, ‘is that many members of the communities believe that it is only important to use condoms with CSWs. This reflects the general belief that CSWs are the source of infection.’⁷

As noted in chapter 2:

- ❖ all African HIV/AIDS projects in the sample worked with the general community;

- ❖ several earlier projects in Asia focused more on specific-population categories, such as commercial sex workers, fishermen, migrants;
- ❖ the community-wide dimension became stronger in Asian projects in the second half of the 1990s;
- ❖ the majority of projects in our sample had a community-wide focus in total or in part.

A bonus of the community-wide, locality-based approach is that HIV/AIDS is presented as a community issue rather than a problem associated mainly with population sub-groups. There are some analogies with the post-war debate on the relative merits of universal and selective social services. Proponents of universal services in health, education, water, gas and electricity argued that they were non-stigmatising and helped bind the community together, whereas selective services (usually means-tested) divided the users (usually the poor) from the mainstream of society.

Negative-living messages

Only two evaluation teams found that the reviewed HIV/AIDS project communicated negative messages that could promote the stereotyping and stigmatisation of PLWA. The final evaluation report of Chiangmai I noted that:

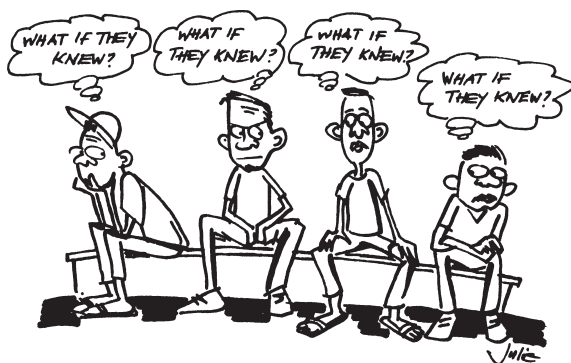
In the early information messages, sex with commercial sex workers was highlighted as a risk behaviour rather than unprotected sex with any partner outside marriage. This is a common error which leads to reinforcement of stigmatisation of commercial sex workers, blaming of commercial sex workers for spread of HIV infection, and complacency over the risk of unprotected sexual practice.⁸

The HIV/AIDS prevention strategy used by Arumeru included messages and images of sickness, wasting and death designed to produce fear of AIDS (and by association PLWA). Some of the AIDS-awareness posters depicted PLWA as emaciated, skeletal, cadaverous figures with skin rashes. The AIDS equals DEATH association was promoted.

Many of the project’s songs, drama and poetry about HIV/AIDS use messages of fear and death. These images become transferred from

the disease to the people with the disease, making it very difficult for the community to live with them without fear. In order to begin to change community attitudes, the project will need to develop new HIV/AIDS education messages which do not campaign on fear.⁹

Some of the Arumeru project staff tended to use language like *victims* or *patients* when speaking of people living with HIV/AIDS and appeared to see the major positive role for PLWA as one of not infecting others. There were other dimensions of the project's strategy that encouraged increased community support for PLWA.



The evaluation team noted the absence of PLWA-related peer support and advocacy in the area and encouraged the project to help PLWA to form their own groups. The evaluation team also noted that PLWA were not included as members of staff and project committees. The evaluation team recommended that the project promote a central role for PLWA in all dimensions of the project structure and functions.

On the other hand, the project was:

- ❖ working with two active, capable and committed PLWA; and
- ❖ training and encouraging other local community volunteers to counsel and care for PLWA.

There were positive signs of community willingness to care for PLWA, a positive sign of acceptance of HIV/AIDS and PLWA as a family or community issue. The project encouraged a higher degree of community acceptance through its example of training community volunteers in treatment and care. See chapter 3 for further discussion of these issues.

Care

There is no evidence to suggest that the care-related messages of the projects were anything but practical and positive. Care-givers need to be trained in prevention methods for their own safety as well as other practical details that vary depending on the role of the volunteers (see Textbox 5.3). Since nine of the 19 projects were involved in establishing and training community carers, it is likely that the training curriculum for care of all nine contributed to *positive living* of PLWA and their families and several evaluation reports presented evidence in this direction.

The Chiangmai II mid-term review report, for example, noted that:

As a result of the education and training strategies launched, a growing number of people in the communities have significantly increased their understanding and knowledge regarding AIDS. There are now some villages in which people feel comfortable with HIV/AIDS infected persons. However, there are still some villages in which people still fear the disease and ostracise those who are HIV positive. Therefore, it is important to continue to provide correct AIDS information and counselling to encourage villagers to build a network of support for those PLWA, as well as each other.¹⁰



Several PLWA interviewed in Kariobangi told the evaluation team that the project had helped them and had assisted to reduce the negative community attitudes concerning PLWA. One female PLWA, a vegetable seller with five children, made comments

supportive of increased awareness during the evaluation (see Textbox 5.4). A second female PLWA in Kariobangi said: 'Since the project has commenced awareness building, the attitudes of the community are changing. Before they wouldn't come near me. Now fear is reducing'. A third said:

Because of this project, people's attitude towards PLWA ... is changing. Because of our messages, they are responding well and no longer isolate us or fear us. They still buy from me when they learn that I have AIDS. But some won't come if they know. Ignorance causes this. Some will even verbally abuse you in public if they know you are HIV positive. To change these attitudes, all we can do is keep visiting villages and persevere with messages. We should concentrate on schools because children are more receptive to change.¹¹

There is little documentation in evaluation reports and project completion reports of the kind and degree of *positive-living* messages used by projects to promote quality of life for PLWA. It is likely that all HIV/AIDS projects, among other things, tried to reduce misconceptions on how HIV is transmitted, misconceptions that would discourage people from associating with known PLWA. In the light of both considerations, *positive-living* education is omitted from Table 5.1 below.

A woman living with AIDS shares her experience

Educating PLWA makes a difference. Before, we were ignorant. We thought we'd die very soon and we worried constantly. Now we know that we are not alone and we aren't going to die soon, even when we become sick. Because of the training, we form groups and share ideas. All this was absent before. Now I don't feel lonely. I don't even have to take solace in relatives, as I have my group for comfort. We meet in the group to discuss our problems and advise each other. If we can't meet our needs from within the group, we approach the project. One or two staff normally come to our meetings. The training we receive is very important. We learn about AIDS and its transmission, how to counsel and protect others and how to reduce the spread of AIDS. Sometimes we receive flour, oil and rice. In times of special need, we may also be helped. I use my training. When I see the symptoms of AIDS I give advice and urge people to go for testing and I teach them how to take care of themselves. I sometimes take part in organized project awareness-

Promoting community care networks

Communities can promote *positive living* for PLWA through the encouragement of treatment and care of PLWA and their families. Peer trainers in Songkhla II, for example, also focused on educating community members on caring for PLWA. These health volunteers used face-to-face discussions, slide shows, video presentations, pamphlets and booklets, 'all of which had been pre-tested before being used'.¹² This project also provided an AIDS information bulletin board for traditional doctors and students at the university given that 'AIDS has many complications and herbs are able to treat some of them'. The Songkhla II project completion report noted that the university would continue to support this activity.

Of the 19 sampled HIV/AIDS projects, nine helped to establish networks of community volunteers and groups whose roles included counselling and care of PLWA and their families. Some evaluation teams reported that these networks had made a significant difference to the lives of PLWA. For example, the Chiangmai II mid-term evaluation report noted that project efforts contributed to 'a phenomenal increase

building activities also. My behaviour has changed because of the training. I still go out, but I insist on using condoms.

Attitudes are changing. Most clients accept condoms, some even carry them with them. My stand is, if he refuses, I leave. I used to warn them that I was positive, but many laughed, they didn't believe me and they said I only didn't want to play! Men are very hard headed. They don't take advice. Maybe using films and newspapers will help to reach them. Some believe what they hear on the radio while others say that business people spread these messages so that they can make more money.

Before I used to be discriminated against. I couldn't share anything. My children were chased away. This attitude is changing because of awareness building by WV and many others, particularly church groups and church classes for educating children on how to care for sick family members. I am no longer discriminated against in my community or family.

Textbox 5.4

Kariobangi Evaluation Report (2001), p. 44.

Iyolwa community counsellors' role in care

About 58 per cent of the sampled counsellors (33) said that they did education^a and care^b activities and 39 per cent named only education activities.

Having nearly six out of 10 counsellors report that they were involved in caring for PLWA and their families is a relatively high percentage compared to the other WV HIV/AIDS projects that were evaluated.

This relatively high percentage of counsellors involved in caring is possibly indicative of counsellors' acceptance of PLWA as continuing community members. Project staff and counsellors usually call PLWA clients (rather than patients or AIDS victims) as in the WV Arumeru HIV project in Tanzania.

¹ Classing all mention of sensitisation, education, mobilising for education, arranging women's groups for education purposes, encouraging use of condoms, telling people to go for blood test, training counsellors, counselling on its own or counselling community as 'education'.

² Classifying all the activities relating to clients (including counselling) as 'care'.

in the number of community groups/organisations established to provide assistance to PLWA' leading to improved community care and acceptance of PLWA, especially in some villages.¹³

Facilitating PLWA associations

Another way of promoting *positive living* for PLWA is to help them to organise themselves for peer support and self-help. Five projects took part in the establishment of PLWA mutual-support associations. The Iyolwa project, for example, helped establish four PLWA associations. In response to the question 'how have associations assisted you or your community?' female members of one of the four PLWA associations established in the Iyolwa project area said:

1. It has brought us in light. *How?* We were hiding this [their HIV positive status] but when the counsellors came we are now in light.
2. It has helped us, the client, to obtain medicine.
3. It has brought us together if you may be sick.
4. They help us to go for blood test.¹⁵

It is also possibly an indicator of the willingness of PLWA in Iyolwa to acknowledge their status to themselves and to others in the community. The project's role in facilitating this relative openness is difficult to discern with precision in the time and available resources.

The role of the project in facilitating greater acceptance of PLWA among themselves and the broader community was often mentioned. Arguably, project staff and volunteers (and PLWA themselves, facilitated by project staff and volunteers) played a significant role in promoting a more positive social climate for PLWA to come out and to live with dignity.

The Ugandan government and various communities, too, deserve recognition for their historical willingness to be more open to acknowledging HIV/AIDS and its effects than counterparts in many other comparable parts of the world. This greater openness is often said to be part of the reason for Uganda's relative success in fighting HIV/AIDS.¹⁴

Textbox 5.5

O'Shaughnessy, T. (2001) *Iyolwa HIV/AIDS Project Evaluation: Technical Advisor's Report*, World Vision Australia, Melbourne, p. 21.

Statements like 'association taught us how to live positively with AIDS' and references to 'reduced fear, people can now come out openly' were made in each of the group interviews with PLWA in Iyolwa in response to questions like 'how has the association helped you?' See also the textbox below, where women of the Gule sub-parish PLWA association referred to the association reducing stigmatisation in their lives. Kawthaung, Nankumba and Danang I evaluations found evidence of reduced fear of PLWA.¹⁶

Textbox 5.7 gives more detail on how the associations and the project have helped PLWA in Iyolwa, Uganda, and suggests ideas for further assistance. The interviewer and notetaker were both community volunteers and the notes below have not been altered.

Of the 19 sampled projects, nine focused on facilitating care for PLWA and their families. Only three evaluation teams (Kawthaung, Nankumba and Mumbai) found that the project under review should have focused more on PLWA.

Azeresi and Yeris

Azeresi Ochieng is among those in the kitchen. She walked from her home, four kilometres away to participate in the evaluation process of Iyolwa HIV/AIDS project. She is cooking together with others for colleagues in the field. Azeresi tested HIV negative in 1997. 'Many of my friends on the village died in the early 1990 but we all thought they were bewitched,' Azeresi said. According to her, the rumour came from her neighbors in 1993 that her husband, co-wife and herself had AIDS. The rumour stemmed from the death of the boyfriend of her co-wife.

Azeresi didn't have much proof to go on as testing was not a very common idea in her community. The government of Uganda, however mainly through radio and community based programs, encouraged people to have blood tests. 'I then tested in 1994 and was negative,' said Azeresi adding, 'but I was feeling feverish most of the time'. It was not until the advent of WV in Iyolwa that Azeresi tested again. 'WV advised me to test,' she said. Her husband is dead. The co-wife is also dead and lots of her relatives too.

Apart from the fact that Azeresi lives with AIDS, she leads a happy life. She blames no one for her sickness. Her smile is something to behold. And she is happy that she has a chance to live happier than her late husband and co-wife. 'Whenever I feel sick, they give me drugs for free,' Azeresi said adding that 'I used to cough, shake and be scared about the disease, but now I can even talk to you.'

With World Vision's assistance, she graduated as a Traditional Birth Attendant (TBA). She extends health services to mothers and herself.

Azeresi doesn't live alone. She has four children aged between 5-18 years. She has taken up responsibility to mother three more orphans. Nicholas Oloni 4, is a son to Azeresi's late sister. James Okyande 5, is the son of her late brother-in-law, while Dennis Emepusi is an orphan formerly living on his own before Azeresi invited him to her home.

Azeresi is a member of a nine-person drama group in Iyolwa (of people living with AIDS). Like her friends in the group, singing boosts her hope for a heavenly life. One of her group members is already dead. 'I pray to God for peace. I pray for ideas on how to take care for these orphans,' Azeresi said.

Azeresi must grow food for the family to help them survive. She has done so successfully, whenever the rains fall. A silo stands out prominently in her compound. Inside it, there is a considerable amount of maize corns and millet. She said it would feed the family for a month up to a season for harvesting cassava tubers. She bought two cows. She does the milking herself and drinks some every morning. When her hens start laying, she has eggs to eat. She is looking forward to having the children learn how to rear the nine hens, two cows and calves, four pigs and two sheep. She believes that the animals are her children's life for the future.

Azeresi said the community counsellor in her village helped her so much when she was down. The counsellor's name was Yeris, and the Iyolwa project had trained her in HIV prevention and in primary health care. Community counsellors like Yeris were called doctor in the local Japadhola language. Yeris collected drugs from the counselling unit at the project office and brought along milk or fruit juice to wash down the drug. Yeris also collected water from a well and brought it to Azeresi's house when she visited. 'Sometimes Yeris comes once a week, sometimes twice a week,' said Azeresi.

Azeresi said: 'Yeris encourages me and brings hope in me. Also, she gathers my children and also counsels them with words of hope. She has helped me to have more hope and to gain a little strength. Now, I can even move up to this place (the project office) from the village four kilometres away.'

Textbox 5.6

Source: Jane Nandawula, Communications Officer, World Vision Uganda with additional material by Tim O'Shaughnessy.

Teams evaluating other projects with an exclusive prevention focus presumably felt that intervention was appropriate given the trajectory of the epidemic at that time. Danang I evaluation remarked that: 'as the epidemic increases over time, there will be an increasing need to plan strategies for the care of people infected with HIV ... the work that has already been done on attitudes towards those infected with HIV will serve as a useful basis for the development of home-based care'.¹⁸

Promoting PLWA participation in response

In general, PLWA were not invited to be central players in the HIV/AIDS projects in the sample of 19 WV projects.

Involvement in education

PLWA were explicitly involved in education in only four projects, Arumeru, Kariobangi and Songkhla

Female PLWA association members in Iyolwa, Uganda: community counsellor's group-interview notes

What does association of PLWA in your sub-parish do?

- In Gule sub-parish, we are doing hand work (hand crafts) and singing and making drama.

What else?

- When one of us dies, we also contribute some assistance during the funeral rite.

What do you enjoy about being in the association?

- It reduces stigmatisation in our life.
- Making hand crafts.
- Playing drama.
- Making friendship with our other member of different associations.

How does the association help you?

- It has created relationships among ourselves.
- Reduces stigmatisation in our life.
- Sharing our personal problems, because when you are at home you think you are the only one who is sick, but when you meet your friend who is also sick and share together your ideas. It is also helpful.
- It has taught us how to prevent and also not to spread [the infection].
- It taught us to stick to one partner.
- It reduces worries as counsellors are counselling us every time.
- It has brought us to light because we were hiding the disease, but through counselling we have managed to come out.
- Getting free treatment.

How does the association help your family?

- They [project] are now free in giving us patient care.
- Not using sharp instruments with more than one person (this was through counselling).
- Using condom when they all infected.
- Avoiding unsafe sex.

How does association help your community?

- The community is now aware of how the disease can be spread and how to prevent it through our drama play.
- It has created relationships in the community.

What could be improved about the association?

- The project would provide loan.
- The project would help in (gift in kind) so that they improve health.
- The project would provide us with strong drugs so that we can live longer.

How would the association help you better?

- If they would provide credit.
- It they would provided enough drugs.
- Project would provide skills such as training in how to manage business.

How do volunteer counsellors help you?

- They provide us with drug when they are sick and on counselling day.
- They counsel us in that case they reduce worries in their life.

What do they do for you?

- Visit us almost every day
- Treat us
- Sometimes they provide food, soap and paraffin.
- Feed us on counselling day (at Gule PLWA Association)
- Giving us patient care for example washing clothes cooking and collecting water.

How could they help you better?

- They would transport us from our home to the counselling centre.
- They would take all the patient care because now they are energyless.
- Give us enough treatment

How does the project assist you?

- The project is providing us with free treatment.
- It has created awareness among ourselves.
- It has created relationships between us and the project officials.
- It has made our children also to know how HIV/AIDS can be spread and how to prevent.
- It has taught us to avoid unsafe sex.
- It has taught us about family planning.
- It has taught us about healthy [habits] for example cleaning our compounds and houses.
- The project provides us with blankets and jackets.

Textbox 5.7

Notes from group interview with female PLWA association members in Gule sub-parish, August 2000, taken by community counsellor.

Table 5.1: Main Ways that Different Projects Assisted PLWA (excluding HIV-awareness components)					
	Community care ¹⁷	Loans to PLWA or caregivers	PLWA mutual support	PLWA advocacy	Comments
Arumeru	✓				Community counsellors involved in counselling and care of PLWA.
Mongla					Exclusive prevention focus.
Highway One					Exclusive prevention focus.
Kawthaung	✓			✓	Project advocated that PLWA have access to hospital when hospital staff refused to work with PLWA; agreement whereby volunteers came in to change dressings, sheets, wash clothes and other tasks.
Chiangmai I			✓		Prevention focus, but PLWA clubs established towards end of phase I.
Chiangmai II	✓		✓		Stronger emphasis on building community care and support capacity for PLWA.
Songhkla I					Exclusive prevention focus.
Songhkla II	✓		✓		
Senegal					Exclusive prevention focus.
Kahama		✓			Exclusive prevention focus in its HIV/AIDS component, but primary health care approach to reduction of infant mortality. Loans were to women to start income-generating activities to increase income and reduce infant morbidity and mortality. Likely that loan recipients also PLWA carers although that was not necessarily the project's primary or explicit intention.
Nankumba	✓				
Iyolwa	✓				Loans were not directly targeting PLWA or families
Mumbai					Prevention focus (with some notable and moving exceptions, see Textbox 5.3).
Danang I					Exclusive prevention focus.
Danang II					Exclusive prevention focus.
Thai-Burma/ Myanmar	✓		✓		
Thanh Hoa	✓	✓			Although PLWA and families not an explicit focus of project, HIV/AIDS-related training and loans to primary health care workers.
Kariobangi	✓	✓	✓		
Total: 19	9	3	5	1	

'People living with AIDS are central to the response' says UNAIDS

At every level, from community to national to international, the benefits of a greater involvement of PLWA have been shown. Stigma and discrimination towards PLWA has been reduced by their visibility and involvement in local, national and international organisations. Their participation in policy, program design and implementation has been instrumental in reorienting priorities, ensuring relevance and effectiveness, and increasing accountability. As advocates for intensified prevention efforts, PLWA have been successful in bringing a human face and voice to the epidemic, challenging complacency and denial, strengthening the call for urgency in the response, and moving governments and their leaders to action.

Textbox 5.8

UNAIDS (2001), *The Global Strategy Framework on HIV/AIDS*, Geneva, p. 7.



II and Highway One. The Highway One mid-term evaluation notes that:

As there were few PLWA during project implementation, WV staff decided not to concentrate on care issues for PLWA. A man living with HIV participated in young people's activities instead. This was a positive experience from the point of view of the man and the young people and was an appropriate way to decrease discrimination against people living with HIV and to provide a livelihood for someone infected by and affected by the virus... All collaborators [peer trainers] participated in training on HIV. Painting activities then commenced in eight hamlets... Five young collaborators visited the Quang Tri Project site to provide training for its youth group in painting and distributing IEC materials. Health checks for women were conducted on two or three occasions. One group of five young women from the painting group were motivated by the HIV preventative messages to distribute materials in local restaurants serving drivers; this was not organised by the project. At first these women were shy and embarrassed but grew in confidence. Their discussions with a trainer who is living with HIV helped their understanding and motivation.¹⁹

Arguably, the practice of including PLWA in all dimensions of HIV responses helps to:

- ❖ promote effective prevention and care;
- ❖ counter widespread denial that HIV/AIDS exists even in places with relatively high prevalence;

- ❖ empower PLWA;
- ❖ promote community acceptance of PLWA;
- ❖ promote the message of *positive living* with AIDS.

A feeling of being respected, useful and a continuing part of the community is an important part of *positive living* for PLWA.

Involvement in project committees

Only one project (Kariobangi) included PLWA in the project management or advisory committees. No project included PLWA on staff. Three evaluation reports recommended that PLWA be involved more widely and centrally in project activities and management, for example, to be included as community counsellors and educators, staff members or members of committee of management (Kariobangi, Arumeru and Nankumba). The Nankumba evaluation report recommended that:

Consideration be given to training a wider range and greater number of peer trainers, including PLWA. Peer trainers should be as varied as their communities, by age, sex, occupation, tribe, class, religion, other special characteristics.

Consideration be given to facilitating greater involvement of PLWA as active and respected

players with much to offer in HIV prevention and care. If possible (a) two PLWA should be members of the future committee of management, (b) PLWA volunteers should be recruited, (c) a PLWA support/advocacy group run by PLWA themselves should be encouraged and nurtured if at all possible. It could be a key indicator of project success! (d) PLWA should be involved in HIV education and care.²⁰

Advocacy

PLWA often suffer discrimination at the hands of fellow-community members, government health staff, private and public sector employers and non-government organisations in the form of:

- ❖ impersonal discrimination where there is a policy of discrimination against PLWA as a category, such as 'we don't employ HIV positive people';
- ❖ personal discrimination occurs when a particular person is discriminated against on the grounds of their HIV/AIDS positive status, such as 'we don't treat you at this hospital because we don't want staff to risk infection'.

Advocacy is an important tool with which to:

- ❖ address discrimination and other injustices;
- ❖ mobilise people and organisations to campaign together;
- ❖ address both immediate and strategic interests of men and women, including PLWA;
- ❖ change laws and policies that block many strategic interests of men as well as women.

Advocacy (to speak on behalf of) should include these three components as far as possible:

- ❖ *Walking the talk*, that is, modelling the different paradigm or idea, in this case a lived acceptance of the *positive living* for PLWA paradigm. Walking the talk, for example, by working and socialising with PLWA (say, through attending funerals).
- ❖ *Blowing the trumpet*, that is, publicising the alternative paradigm (through drama, songs, peer education, pamphlets, billboards, radio and television spots etc.).
- ❖ *Getting down to tin tacks*, that is, issue-specific

advocacy, such as, taking up a test case of discrimination against a particular HIV positive person in the workplace or an organisational policy prohibiting employment of HIV positive people. In addition it could involve facilitating PLWA to advocate on their own behalf with continuing support as campaign partners.

Evidence of action on all three of these components was thin in the sample of HIV interventions given that these precise functions were not spelled out as such in project proposals that guide most evaluations and project completion reports.

Walk the talk

Of the 19 projects, eight worked to develop the capacity of community volunteers to support PLWA and their families. This could also be called *advocacy by example*, speaking on behalf of PLWA by showing that project staff and community volunteers accept and wish to assist PLWA. The Chiangmai I evaluation team note, for example:

It is apparent that the project staff are already becoming actively involved in forming relationships with the communities in which they work. An example of this occurred during the evaluation where project staff attended the funeral of a peer trainer who died from the virus. Such behaviour has an impact on the way in which these communities react to the threat of HIV/AIDS and relate to PLWA and is commendable.²²

Blow the trumpet

Project publicity campaigns (via posters, radio, song etc.), appeared to have focused on risk reduction rather than *positive living* for PLWA. Of the 19 projects in the sample, 11 focused exclusively on HIV/AIDS prevention.

Some projects appeared to have publicised the dimensions of care and PLWA. In Kawthaung, a local community development volunteer (CDV) wrote and produced an opera on her own initiative from her own experience of nursing a fisherman dying of HIV/AIDS and later assisting his orphaned children. The opera was videotaped during a performance. Copies were made and used by the project manager and CDVs as an educative tool on prevention and care.



In general, the split approach taken by Songkhla II described below was probably typical of most projects:

The project showed slides in the various communities. Hundreds of people, mostly young people, joined these activities. The project also distributed information education communication materials during these slide nights. The project distributed information on AIDS to 15 beauty salons during this period but did not implement any training sessions, because many of the beauty salon workers refused to participate in the training session due to a lack of free time and probable loss of income. Therefore, the project staff had one-to-one conversations about AIDS with these workers. From these conversations, the project staff realised that the project should disseminate information to the beauty salon workers focusing directly on accepting PLWA and the need for clean equipment.²³

As in Songkhla II, it is likely that most projects' high-profile, large-group education was on prevention while lower-profile education on care was undertaken in smaller groups of people who had volunteered to be community HIV/AIDS activists. This strategy was presumably influenced by the sensitivity and stigma of HIV/AIDS and PLWA among the community. Unfortunately, space precludes giving more detail on the breadth and depth of the fear, denial and stigma concerning HIV/AIDS and PLWA in project communities as a typical and difficult constraint on project's promoting *positive living* for PLWA and placing PLWA at the centre of the HIV/AIDS response. Few PLWA are willing to come out and

publicly acknowledge their status and become visible PLWA activists. Few families are willing to publicly acknowledge that family members are PLWA.²⁴ Working to improve this situation will promote *positive living* for PLWA and help preventive efforts as well.

Get down to tin tacks

There is no evidence in the evaluation reports that any project worked to develop the capacity of PLWA to advocate on their own behalf to change rules, roles, practices and attitudes.

The Iyolwa, Chiangmai 1 and II, Kariobangi projects and one program (Thai-Burma/Myanmar) facilitated the development of PLWA support groups, but these were usually to help build peer support while simultaneously providing a convenient forum for the project to provide or offer counselling, medical and nutrition services. In Kariobangi, the PLWA group appeared more multidimensional and outward-looking than most other PLWA groups—it was a mutual-support group, a loan group and a group of activists involved in prevention.

None of the project proposals included advocacy as an explicit component. *Direct advocacy*, whereby the project advocates on behalf of PLWA, was not seen; nor was *advocacy-capacity-building* where the project helps develop PLWA capacity to organise and advocate on their own behalf with ongoing project support as campaign partners. However advocacy did occur in some projects. The Kawthaung evaluation team heard that the project opened up hospital care for PLWA by offering and providing volunteers to do what hospital staff would normally do for patients. It was hospital policy for nursing/cleaning staff to avoid PLWA. Arumeru project participants acted as advocates for PLWA and their families in encouraging agricultural extension workers to assist PLWA and their families to establish and maintain nutritious kitchen gardens.²⁵

Danang II's excellent work in advocating harm reduction also illustrated the three pronged advocacy approach:

- ❖ modelling a compassionate-pragmatic harm reduction approach in its own work and

attitudes to injecting drug users and commercial sex workers;²⁶

- ❖ conducting workshops and study tours for government staff, publicising harm reduction as an alternative to the mainstreams social evils approach of the government;
- ❖ advocating on specific issues and tensions via frequent meetings with key stakeholders.

Overall, advocacy in general and specific to PLWA issues was an undeveloped possibility in the sample of HIV/AIDS projects.

Financial support to PLWA and families

A UNAIDS priority for reducing the impact of HIV/AIDS on individuals and families is to give ‘direct support to reduce the catastrophic financial impact of HIV/AIDS on families’.²⁷ Yet only three projects offered loans to PLWA and potential carers (Kariobangi, Thanh Hoa and Kahama). One of the loan groups in Kariobangi consisted of PLWA association members. PLWA loan recipients interviewed by the evaluation team spoke of the difference the loans made. The small income-generation activities enabled by the loans were often the difference between having an evening meal and not eating that evening. For example, two of the seven women interviewed mentioned that they were now in a position to avoid engaging in sex for money or to have sex only with men willing to wear condoms. It is worth noting that the project had a 100 percent loan-repayment record.²⁸

The Thanh Hoa project offered loans to local primary health care workers to encourage these government workers to maintain their roles given the government’s difficulty in maintaining their remuneration.

Kahama offered loans to local women to start income generating activities to help raise household income and ultimately to reduce infant morbidity and mortality. Although it is not discussed in the evaluation report, many of these women were likely also to be carers for sick fathers, brothers and sisters, aunts and children.

Towards positive living

Several evaluation teams heard evidence that community fears towards PLWA were reduced, and that projects had assisted in the reduction of fear and stigma (Kawthaung, Arumeru, Iyolwa, Kariobangi, Chiangmai II, Thai-Myanmar, Danang II). A few evaluations reported evidence from PLWA themselves that the project had helped them to help themselves to improve their lives—and often those of their family—dramatically (Arumeru, Iyolwa, Kariobangi). In most cases, the same informants were active in HIV/AIDS prevention and care activities.

Suggestions for the future

Organisations supporting HIV responses could consider the following suggestions:

- ❖ committing to promoting and mainstreaming the positive-living principles described in this chapter through all phases and dimensions of HIV/AIDS responses, including project design, appraisal, implementation, management, monitoring and evaluation and organisational life/policy more generally;
- ❖ implementing the more detailed design and appraisal suggestions made in the previous chapter concerning GAD and broadening them to include and promote the *positive-living* approach.

Summary

The HIV program as a whole has not been strong in helping to place PLWA at the centre of HIV responses. Just over half of the sampled projects focused exclusively on prevention (most of them were working at a time when few PLWA were visible in the community).

Of the nine projects focusing on care and other PLWA-focused activities, most worked through volunteers to provide counselling, care and some treatment-related support for PLWA. Helping to develop the community and government infrastructure to support PLWA and their families was a major contribution towards a positive environment for PLWA. Although not evaluated or documented as such, it is

likely that most projects had a positive effect on acceptance of PLWA through their education on how HIV is transmitted and not transmitted, thereby reducing some of the more irrational fears concerning infection by any kind of association with PLWA.

Few projects provided loans to support PLWA and/or their carers. Only one project included PLWA as members of a project committee. Three projects actively involved PLWA in prevention roles. No project included them as staff members. Five projects facilitated the establishment of PLWA mutual-support associations. Three evaluation reports recommended that PLWA be involved more widely and centrally in project activities and management, for example, included as community counsellors and educators, staff members and members of committee of management.

Advocacy was not a key part of any of the projects in the 19 projects reviewed. The key findings:

- ❖ Concerning the first element of a good advocacy approach (*walking the talk*, modelling the alternative vision as far as possible):
 - * nine projects that facilitated community networks of support and care for PLWA thereby demonstrated a level of acceptance of and solidarity with PLWA;
 - * other evaluation evidence shows some projects' modelling acceptance of HIV/AIDS and of PLWA (Iyolwa, Mumbai, Chiangmai 1, Kariobangi).
- ❖ Concerning the second advocacy element (*blowing the trumpet*, publicising the alternative vision):

- * most publicity campaigns appeared to have focused on risk-behaviour reduction rather than promoting *positive living* for PLWA.

- ❖ Concerning the third advocacy element (*getting down to tin tacks*, taking a specific advocacy issue with coalition partners as a campaign strategy, especially facilitating PLWA to advocate on their own behalf):

- * evidence showed some projects engaging in issue-specific advocacy to promote *positive living* for PLWA, but no evidence of project's facilitating PLWA to advocate on their own behalf. No project design included direct advocacy or advocacy-capacity-building as a component.

The sampled HIV/AIDS projects in general gave a low priority to realising the best-practice principles of promoting positive living and putting PLWA at the centre of their response. That would suggest a low rating. Yet it is worth noting that the projects focusing entirely or mainly on prevention in the first half of the 1990s were consistent with contemporary aid-donor and host-government priorities. This prevention focus was generally accepted without question by contemporary evaluation teams.

The extraordinary stigma associated with HIV positive status will continue to be a significant obstacle in the path of projects trying to put PLWA at the centre of their responses in future. It is worth putting enormous energy into changing this situation to improve HIV/AIDS prevention and care and to help PLWA realise their basic human rights.

Notes and References

¹ O'Shaughnessy, T. (1994) *Beyond the Fragments: HIV/AIDS and Poverty*, World Vision Australia, Melbourne.

² See, for example, Mann, J. and Tarantola, D. (ed)(1996) *AIDS in the World II*, Oxford University Press, Oxford.

³ UNAIDS (2001) *The Global Strategy Framework on HIV/AIDS*, UNAIDS, Geneva, p. 14.

⁴ Danang II Evaluation Report (1998), p. 28.

⁵ See O'Shaughnessy, T. (1994) *Beyond the Fragments*, World Vision Australia, Melbourne.

⁶ Songkhla 1 Evaluation Report (1993), p. 29.

⁷ Chiangmai 1 Evaluation Report (1993), p. 15.

⁸ Chiangmai 1 Evaluation Report (1993), p. 24.

⁹ Arumeru Evaluation Report (1999), p. 41.

¹⁰ Chiangmai II Evaluation Report (1994), p. 6.

¹¹ Kariobangi Evaluation Report (2001), p. 42.

¹² Songkhla II Project Completion Report (1996), p. 24.

¹³ Chiangmai II Evaluation Report (1994), p. 25.

¹⁴ Iyolwa Evaluation Technical Advisor's Report (2001), p. 27.

¹⁵ Iyolwa Evaluation's Technical Advisor's Report (2000), p. 8. Numbers in the quote refer to different people in the group individual. The notetaker was following the convention of

giving each individual a number and associating the comment with the speaker.

¹⁶ Kawthaung Evaluation Report (1999) and Danang I Evaluation Report (1996). Among other things, both evaluations refer to former indecent haste in burying people suspected of being infected with HIV. Kawthaung evaluation team was told of former practice of PLWA being taken and left outside the cemetery to await their death.

¹⁷ Volunteers and staff of all World Vision-assisted HIV/AIDS projects involved in facilitating community care for PLWA were also involved in counselling and facilitating treatment for PLWA and their families. So, the heading 'care' also includes counselling and facilitating treatment as well as project staff facilitating the training of carers.

¹⁸ Danang I (1996), pp. 51, 53.

¹⁹ Highway One Evaluation Report (2000), pp. 15, 21.

²⁰ Nankumba Evaluation Report (2000), p. 8.

²¹ These ideas are based on my own experience of advocacy in Australia and overseas as well as on a review of best-practice in advocacy that Dr Ted Vandelloo and I wrote in 1995 as a World Vision Australia internal paper.

²² Chiangmai I Evaluation Report (1993), p. 24.

²³ Songkhla II Project Completion Report (1996), p. 23.

²⁴ Issues of stigma, fear, secrecy, low visibility of PLWA are mentioned in several evaluation reports (eg Arumeru, Kariobangi, Kawthaung, Nankumba).

²⁵ Given limitations on size of evaluation reports, not all significant information is included in evaluation reports. Neither of these examples appeared in the evaluation reports, but I know of them because I was involved in the evaluation. Similarly, it is possible that there are other examples of low-visibility advocacy that have not been documented.

²⁶ Personal communication, Mr Hanh, project counsellor, 1995.

²⁷ UNAIDS (2001) *The Global Strategy Framework on HIV/AIDS*, UNAIDS, p. 11.

²⁸ Kariobangi Evaluation Report (2001).

