Danger and Opportunity:

Responding To HIV With Vision

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Abstract

This article presents some examples of successful and innovative community-development work which has focused on HIV and gender relations, and gives a personal view of ways in which the danger of HIV can be used as an opportunity to address many issues which have always been there, but which, until the advent of HIV, few have dared to think about.

Among trainers in participatory approaches to development, there is a legendary indigenous language which uses one character to represent the concepts of both 'danger' and 'opportunity'. This symbol, which simultaneously represents two very different attitudes to a situation, reminds us of different ways in which people have responded to HIV/AIDS. HIV has now been an issue of major concern for at least 20 years and continues to pose immense challenges, which humanity has been unable to meet. Yet many individuals and groups who are infected with HIV, or touched in other ways, have risen to its challenge. One key example is Noerine Kaleeba, who founded TASO in Uganda in 1986 (Hampton 1990). We feel that development workers owe it to extraordinary people like Noerine to consider what opportunities may be presented by the danger of HIV.

The difference between the agendas of health personnel and other development professionals and those groups who are targeted for their attention has been a problematic aspect of much HIV work in the past. Most have set their own agendas in response to HIV, and have developed an ‘us and them' approach, focusing mainly on prevention work

among groups of people who are viewed as 'vulnerable groups' and from whom workers can distinguish themselves clearly. Sex workers are one such example. However, some programmes and projects have taken a much wider approach, contextualising the health issues inherent in HIV within their social context. Below, we give some examples of such innovative work.

The Working Women's Project: understanding people's own priorities

In Bradford, a city in the north of England, the Working Women's Project was established in early 1991, in response to growing public concerns about HIV. Public funds for the Bradford project were earmarked for 'HIV', and the project was ostensibly conceived to reduce infections within the population of sex workers and beyond. It was widely assumed by the health service and the local authority that in order to stop the spread of HIV infection in the UK population, sex workers (who sometimes refer to themselves as 'working women') should be targeted for HIV education. Of course, as with so many similar projects, it did not take long to establish that sexual health was not a high-priority issue for many of the sex workers. Their priorities were, rather, to avoid arrest by the police and violence from clients, police, and pimps; to care for their families; and to achieve economic solvency. Health was at the bottom of their list. It is unsurprising that sex workers in many other parts of the world share these same priorities.

Responding to the views and agendas of groups 'targeted' for development work necessitates moving beyond a narrow focus on a project, to concentrate on attitudes and approaches. In Bradford, HIV prevention was the agenda of the health authority, and not of the women. As project workers, our job was to navigate the grey waters in between. In Bradford, establishing credibility with the sex workers themselves, and building a project which went some way to meet their needs, involved many years of listening and responding. After the first year, a group of women approached the project staff (of whom Kate Butcher was one) to say that they were heartily sick of reading articles about 'prostitutes', which bore no or little relation to their own experience.

Collectively, it was decided that those women interested would contribute their experiences to a book, which would not be edited in a way which integrated a social analysis, but would rather be a stand-alone book of testimonies 'in our own words', whose contents could therefore neither be refuted or approved: it was simply to be a collection of their own stories in their own words. The book took over two years to produce. It was pulled together from very loosely structured interviews with eleven women. Each chapter begins with a poem written by one of the sex workers, and the final poem is a contribution by a client. The process of putting the book together was an empowering one; women began to see points of commonality in their lives, rather than issues which encouraged competition between them. It was agreed among them that the book should be dedicated to the three women who had died during the first two years of the project, two as a result of violence and one from a drug overdose. It was a powerful reminder of

the centrality of violence in sex workers' lives. Those who contributed to the book came together again over a year later, to organise a memorial service for one of their friends who was murdered on the street. Obviously, this was a tragic and traumatic time, but the sex workers were determined to make their voices heard. There is no magic formula to guarantee the success of such an activity, simply the willingness of those employed to work with different communities to listen to people, and to respect them as equals.

The concept of sharing experiences with women was critical to the success of the Working Women's Project. Kate Butcher went on to work in Nepal in a different capacity, but continued her links with sex-work projects. During this time, she ran a workshop with sex workers in Kathmandu for the British Council (Butcher and White 1997). The workshop was designed to help women to identify their major concerns about their work and then to share and develop coping strategies. The common issues of concern to both sets of women were far removed from the HIV-prevention agenda of the professional health staff in their respective countries. As key issues in their lives, the 30 Nepalese sex workers clearly identified violence at work and at home, and intimidation and violence from the police. There was a deep-rooted commonality in the collective experiences of these women from Bradford and Kathmandu. At the end of the week, Kate Butcher invited women to use a hand-held video camera, to send messages to sister sex workers in the UK. They were encouraged to ask questions. They asked about the rates that women charged for their work in Bradford, and recounted their own stories of arrest, or strategies for avoiding violence or police harassment. When I showed the video in Bradford, the women there could scarcely believe the similarity to their own experiences. (They were also amazed that anyone could actually 'do business' in a sari!)

It was only by addressing and recognising the issues fundamental to women's lives that we were subsequently able to go on to work with them on the issues of HIV prevention and improved sexual health. In a sense, we ended up with a reciprocal arrangement between project workers and the women themselves, in which we acknowledged the importance of violence or housing or children in their lives, and they in turn acknowledged the importance of achieving and maintaining a good level of sexual health.

Supporting positive people in their response to HIV

In the past, health and development workers have often viewed people with HIV and those perceived as 'at risk' as objects of blame, or, at best, of pity. Most agencies have assumed that once people are HIV-positive, they are really a lost cause. There are a few notable exceptions who have focused on care and support for those who have HIV, and even fewer who have viewed HIV-positive people, or others in marginalised groups seen as 'at risk', as equal actors who can play a central role in responding positively to the challenge of HIV.

There have been many responses from people living with HIV to negative attitudes towards their condition, including a great frustration with judgemental, insensitive, and

irrelevant approaches from health workers. For example, in 1998, the International Community of Women Living with HIV, an NGO founded in 1992, launched its own research project to study the needs and perspectives of positive women, called Voices and Choices (Feldman *et al*., in press). In Zimbabwe, positive women from many different backgrounds worked together with other women on the steering group, underwent training in interview techniques, and developed their own set of questions for the research project. From work with groups of positive women all over Zimbabwe, key findings included initial reactions of blame and anger from family members; the huge loss of income faced by positive people and their families from loss of property and labour, through both stigma and ill health; lack of access to health care and children's education through poverty and stigma; lack of access to information about *living* with HIV; social expectations which made women powerless to gain access to or use condoms; fears about infecting children; and the impact on widows of male-biased inheritance laws. The women commented that they had gained huge support from other positive women in local peer groups, and that the development of counselling services had also helped them to begin to address some issues concerning unequal gender relations with their husbands. For the most part, however, although HIV-prevention information was widespread, it had never seemed relevant to them before their diagnosis, since they had not seen themselves as being at particular risk of infection. They said information had not given them the tools to address any of the issues with their own partners, either before or since.

Since conducting the Voices and Choices research, many of the HIV-positive women involved have developed the self-confidence to join local health committees, have engaged in public speaking, and have attended workshops on gender violence and other related matters. They have also networked with other relevant groups in Zimbabwe. The experiences of the positive women of Zimbabwe echo the concerns of the sex workers of Nepal and Bradford, raised earlier. They touch on issues of poverty, violence, and stigma; of a wish for children; of lack of choice - a reflection of the huge range of issues relating to gender and poverty which were in existence for many years before the advent of HIV. Now, ironically, HIV is itself becoming such a great threat to health and life that funding is available and there is a preparedness to begin to address these sensitive (often taboo) issues in ways which never before existed.

Nurturing alternative views: involving men in HIV-support services

While gender-related issues affecting women have been a key and growing concern for development and social policy, the resultant programmes and policies have often failed to get to the heart of the problem, which is rooted in intimate relationships between women and men. Transforming the relationships between women and men demands attention to male gender identity, and the role of men in preventing violence and promoting reproductive health. Attention must also be paid to the achievement of other social goals, including responsible parenting. One particular area of taboo for men is the need for them to be engaged in the process of challenging gender-based inequality and gender stereotypes. Men need to be engaged, partly because of their role within families as

gatekeepers (if they were not themselves involved and did not agree to the discussions, they could ban their wives from attending discussions about women's roles -- and beat them if they disobeyed), but also because they have their own gender-related concerns and needs in terms of sexual health. Although those working in the field of gender have for many years known and struggled with the need to involve men in gender analysis, and the development of gender-aware policy and practice, there is now an increasing international awareness among (largely male-dominated) senior NGO staff (and large donors too) of the importance of sound gender-based work with men in the fight against HIV. The example below, from Brazil, illustrates how this can be done.

Promundo is an NGO working in the *favelas* of Rio de Janeiro, Brazil (Barker, in press). Its activities include work on gender inequality, health, and issues facing adolescents; prevention of intra-personal violence, including gender-based violence; and provision of support to families living with HIV. Promundo has developed an action-research project to work with young men in a context where domestic violence is widely seen as normal behaviour: a powerful image of manhood for these young men. Women are popularly viewed as sexual objects who must always be faithful, whereas men are entitled to have occasional sexual relationships with other women. Links between domestic and sexual violence are also related to unemployment, a history of physical violence in childhood, and a prevailing silence among men about the violence which they see around them.

When the project was still in its research phase, Promundo staff realised that there were often one or two young men in a discussion group who viewed the world differently, and had the self-confidence to question in front of their peers the established view that violence against women was justifiable in order for men to maintain control over their behaviour. Promundo then developed ways of working with these few young men, helping them to analyse the background of violence in their lives and to explore alternative, more positive ways of behaviour. Some older men, who had already formed a group called 'Male Consciousness', were invited to collaborate in the work, acting as positive role models for the younger men. The latter, in turn, were hired as peer promoters.

The peer promoters and other young men wove their own personal stories into a play and a photo novella, entitled *Cool Your Head Man*. The play, which explores relationships, domestic violence, and health issues, is currently presented widely around the *favelas*, and the photo novella is distributed among the audiences. The photo novella enjoins men to 'reflect before they act, and to cool down when they are angry, rather than use violence'. This project is only in its infancy, but through engaging with these young men, their partners, parents, and opinion leaders, it is beginning to build on those few exceptions to the norm which already existed, to explore different ways of viewing violence in the community. The project is based on the recognition that there is a long way to go to challenge ingrained attitudes to gender relations and violence, but that, through building on existing awareness and through encouraging the development of local materials and performances, a sense of local ownership of the project can be built, which will enable its success to spread.

Working from different starting points: Stepping Stones

Another programme which takes a wider approach to HIV than the narrow health-focused model is Stepping Stones, a training package designed for community-wide use (Welbourn 1995). Initially produced as a resource for rural communities in sub-Saharan Africa, with a strong emphasis on HIV and gender issues, it has now been successfully adapted and translated by various organisations, in many different contexts (Gordon and Phiri 2000).

These local adaptations have been a key part of the success of Stepping Stones. This is because, although the package covers many different issues (such as responses to the use of alcohol; patterns of access to and control of money in the household; gender-based violence; ways of building self-esteem, assertiveness and effective communication skills; and even preparing for death), the central focus of the original manual was HIV. However, as we have tried to show above, HIV is normally not the issue at the front of the minds of the people with whom we may be trying to work. This is true even of people in countries with a high prevalence of HIV, such as Uganda. For instance, after a Stepping Stones workshop there, young women reported that they were now able to negotiate condom use and were glad that they could do so, because it would protect them from ... *pregnancy*. They were more immediately fearful of being expelled from school because of pregnancy than of contracting HIV (personal experience 1996). It follows from this that, if international funders rush in to promote their concerns about HIV (especially in countries where the prevalence - at least officially - is still low), there is a great chance of doing more harm than good.

As an alternative approach, programmes run by the Planned Parenthood Association of South Africa and the South African Medical Research Council Women's Health Unit in South Africa (Jewkes *et al*. 2000), and in Gambia by the Gambian Family Planning Association, the British Medical Research Council, ActionAid, and others, have successfully adapted Stepping Stones to suit local concerns by presenting the package as a fertility-protection programme (Shaw and Jawo 2000). People in both these countries, one with high HIV prevalence, one with still relatively low HIV prevalence, are anxious to maintain their fertility. In Gambia, a polygamous society, there were also fears that Stepping Stones was yet another Western-inspired population-control programme. By presenting Stepping Stones as a programme which will enable couples to have children when they want to do so, as well as protect themselves from the STIs which often cause infertility, staff have successfully developed the package in a manner which has been well received. By starting off with what concerns participants most, facilitators have been able to earn their trust, which has in turn enabled them to go on to address other related issues.

In the programmes of both countries, as elsewhere in contexts in which Stepping Stones has been well adapted and well facilitated, participants have identified the positive outcomes as a reduction in gender violence, increased sharing of household expenditure,

an increase in condom use, reduced alcohol consumption, more equitable inheritance, more satisfaction in sexual relations, and a reduced number of sexual partners (Welbourn 1999). The staff in the programmes concerned also comment that it is now possible to find words to talk about issues which until now have been entirely taboo subjects.

It is ironic that, so much money having been spent on population-*reduction* strategies over the past 20 years, an approach to HIV/AIDS prevention which can be presented as a fertility-protection strategy should now show signs of achieving so much. Once more, work on HIV seems to be teaching development and community workers - at last - the importance of beginning with local people's own agendas, rather than with their own.

Supporting traditional service-providers

Another arena where HIV might be beginning to make a difference is the care and support of sick people. Women have long been seen by gender analysts as 'triple providers', in their productive and reproductive roles, and as community-maintenance workers. In caring at home for loved ones who are sick, women yet again bear the brunt of the workload. Pioneering organisations have evolved, offering support to positive people, such as TASO in Uganda (Hampton 1990) and Chikankata in Zambia (Williams 1990). In the mid-1980s, these courageously began to care for people with HIV and AIDS and their families, and provide non-judgemental support services. At that time, their approach was unique. Yet even these organisations, and those which followed their example, have still done little to challenge the traditional gender models which represent women as the sole providers of such support.

However, signs of change are beginning to appear. In Cambodia, for instance, KHANA, the Khmer HIV/AIDS NGO Alliance, is now working with men, not only to raise their awareness of HIV and their role in prevention, but also to promote their role in providing care for the sick. 'Men have a crucial role to play... and the LNGOs are beginning to work with men in their local communities to identify strategies to do so. Peer group discussions raise awareness of issues such as discrimination and human rights and explore the role men can play in meeting care and support needs in the community.' (Sellers *et al*. in press)

The advent of HIV has also raised awareness among development workers of the key role which traditional community healers have to play, both spiritually and physically, in care and support of people with all kinds of problems. While most development workers in the past have kept well clear of traditional healers, believing that their role was to promote a narrow Western biomedical model of health care, some others have begun to work with traditional healers to promote a more holistic approach to HIV. In Uganda in 1992, one innovative group of traditional healers and doctors joined hands to form a new group called THETA (Traditional and Modern Health Practitioners Together Against AIDS). Displaying mutual respect, trust, and a spirit of openness on both sides, they worked hard to overcome more conventional rivalries and hostilities (Kaleeba *et al*. 2000).

THETA first conducted a study of the efficacy of certain traditional herbs for treating problems common among HIV-positive people, such as herpes zoster and chronic diarrhoea. There were marked improvements in the health of those involved in the study. Subsequently, a second project developed, called THEWA (Traditional Healers, Women and AIDS Prevention), which developed a gender-sensitive, culturally appropriate strategy for educating and counselling people about HIV/AIDS. Out of this then grew a third initiative, which trained healers from eight districts in Uganda as HIV-prevention educators and counsellors. The training sessions, based on the participatory skills in which the trainers themselves had been trained, proved very popular.

An evaluation of THETA in 1997-98 showed some major changes in traditional healers' knowledge of and attitudes towards HIV, their ability to share this knowledge with others, their capacity to counsel others, and their readiness to promote condom use. One spiritualist healer explained: 'We requested our ancestral spirits to understand the serious situation we are in, and they have allowed us to talk about condoms and to promote condoms.' Referrals from traditional healers to Western health-service providers, and *vice versa*, now take place regularly, as each group of providers grows to recognise the limitations of its own services, and the scope of the other's skills. Traditional healers have also supported the development of positive people's own support groups. Above all, they have helped positive people, their families, and communities to cope better with the impact of HIV and to reduce its spread.

Changing attitudes through working with authorities

While providing and facilitating communal, spiritual, and physical support are all crucial elements of a positive response to HIV, the case studies of the Bradford and Nepalese sex workers, and the HIV-positive women in Zimbabwe also reveal their fear of the authorities. The sex workers were concerned about police harassment; the positive women in Zimbabwe were concerned about laws which favour male inheritance systems. Some organisations have adopted strategies to change the attitudes of the authorities, and challenge the discriminatory rules and systems over which they have jurisdiction.

The Musasa Project, a far-sighted and enterprising NGO in Zimbabwe which works to eradicate violence against women, began to work with the police and the judiciary in 1988, with the objective of fostering a greater understanding of the ‘rape culture’ and tolerance of domestic violence which Musasa argues exists in Zimbabwe (Stewart 1996). Few Zimbabwean women dared to report incidents of violence against them, because women often blamed themselves for these attacks, and the police and members of the judiciary often added to this sense of blame through their insensitive and accusatory responses. Musasa managed to work closely with the police and judiciary to develop new, more private reporting processes which were both quicker and more sensitive to the women's needs. A faster, simpler approach to the whole system was developed with the police, to bring the accused to court, treat what the women said seriously, and prosecute rapists. Musasa highlights the close collaboration with the authorities as a key part of its

success. Since those early years, Musasa has developed to do further work with victims of domestic violence.

While Musasa's work did not specifically arise out of an aim to respond to HIV, it now also works closely with organisations such as WASN (discussed earlier), in a collaborative response to HIV. It has begun to focus on the entire range of activities related to HIV and ST1s, including counselling and legal services, public education, and advocacy work.

'Mainstreaming' responses to HIV into the work of development agencies

As HIV continues to wreak havoc in the poorest parts of the world, it has taken too long for development workers to recognise that the impact of HIV and AIDS extends far beyond the areas of concern of the formal health sector: the illness and deaths of large parts of the population - including young and middle-aged adults in the prime of their productive years - result in social and economic fragmentation of society. In many ways, the most acute challenges are yet to come, because the time-lag between infection and eventual illness is long, and the enormity of the problem in some parts of the world - for example, South Asia and Eastern Europe - is only now becoming obvious. However, particularly in areas of the world where HIV took root sooner, the social and economic impact of HIV on livelihoods and all other aspects of human life is now evident.

Consequently, many more development workers are now becoming engaged in thinking and planning which integrates HIV-awareness into all aspects of their work. In particular, they are considering ways of communicating the messages about prevention to as many people as possible in as many ways as possible. 'Mainstreaming' HIV offers an opportunity to address a range of issues which seem to fall through the cracks of standard development work: namely how people relate to each other at work and at home, and how destructive situations can be changed for the good of all. No longer the preserve of formal-sector health workers or health promoters designing their Information, Education, and Communication (IEC) campaigns, HIV-awareness is being mainstreamed into all development activities in a welcome - if tardy - recognition that it is not only people who attend clinics who are vulnerable to HIV, or put others at risk. An opportunity is now opening up to address the issues of intra-personal relationships which have always been a problem, and have always had an impact on people's social and economic well-being, no matter whether there is a high or low prevalence of HIV.

Recently, a training workshop was developed for technical staff and administrators employed by the UK government's Department for International Development (DFID), in an effort to up-date all workers' understanding of HIV and AIDS and to help them to work through the issues which it raises in the workplace (Butcher and Butler 2000). The workshop has been conducted for several departments of DFID in the UK, and also in some of its overseas offices, including those in Nigeria, Pakistan, and India. The package was designed largely to help advisers and technical staff - both British and national - to

think more creatively about their work and to identify areas in which they may be able to contribute to the fight against AIDS, whether in the workplace, or through their development programmes in sectors such as health, education, and governance. The workshop provides participants with opportunities to explore the broader implications of HIV, both personally and professionally.

In Pakistan, a country with an apparently low prevalence of HIV, the participants on the workshop course were mostly administrative workers from the UK Foreign Office, working at a local level. They had little responsibility for the development of DFID's programme. Initially, it was felt that the outcomes of the day might be hampered by lack of input from a programme perspective. However, this was not the case. By concentrating in a gender-sensitive and non-threatening environment on what mattered to the participants, other issues were raised which we had overlooked. For instance, one woman mentioned her relief at attending the workshop, which was giving her a better understanding of the epidemic, but also voiced her concern that she would have to talk about HIV with her prospective husband. She wondered how could she do that, in a society where sex is not openly discussed between women and men. Another woman mentioned rape and the concomitant threat of becoming infected. Regarding workplace issues, the two-day session pointed out clearly the responsibility of the employer to provide a confidential and competent counselling service to all employees who may require it. Happily, at the end of the mission two independent external counsellors were identified, and DFID plans to make their skills available to its employees (and their partners, if they wish).

Domestic violence and emotional stress had already been noted as having an impact on work performance, but they had not been addressed in any clear way before. The HIV workshop allowed a frank exchange of ideas and provided an opportunity for participants to discuss these issues. As a result we were able to identify referral points for staff seeking support, whether their concerns were directly connected with HIV or with relationships in general. DFID has now adopted an internal plan to 'continue to raise awareness among staff of HIV/AIDS issues, including their own vulnerability to HIV', and to address care and support issues for staff with HIV (DFID 2001).

Conclusion

It is promising that development organisations, including large international NGOs and major bilateral donors, are now starting to encourage their own staff to make the links between their professional and personal lives, so that at last barriers between 'us and them', which have for so long prevented the acknowledgement of the impact of HIV on the lives of *all* of us, may be removed. There is a danger here that traditional approaches to HIV may be developed as an after-thought to existing projects, such as engineering, water, or forestry projects. The corresponding opportunity is to build on the lessons offered by innovative approaches, like the ones we have described here. Lack of space prevents us from describing many more kinds of intervention - for example, work with

religious leaders, with older women on female initiation, with men who have sex with men, or with people in same-sex relationships.

Overall, we have gained from these innovations a greater appreciation of the following needs:

- To involve, whenever possible, the people who are the focus of development and community work, and their loved ones, in the planning and development of needs-based responses. In this article, we have given examples of sex workers, young men, rape survivors, development-agency staff, and HIV-positive people. Whoever they may be, they need to be involved.
- To engage men, as well as women, in the response, in reflection of their traditional roles as gatekeepers, as well as their own sexual and reproductive health needs.
- To develop a gender-aware response which addresses the strategic needs of women and the benefits to both women and men of more equitable access to and control of material goods and services; to engage local people in local production of their own communication materials, in order to ensure a local sense of ownership of the changes they wish to see.
- To develop responses to HIV/AIDS not only in countries where HIV prevalence is already known to be high, but in countries with low prevalence, to keep it that way. This is in recognition of the links between poor sexual health and domestic violence, gender inequalities, and poverty which are already prevalent in many countries.

We have tried to highlight the need for a collaborative, multi-layered response to HIV/AIDS from the development community, from bilateral agencies and civil-society organisations together, both internationally and nationally. This response needs to take place at many levels: at community level, through traditional and formal-sector service provision, through religious and political leadership, through workplace support, and through legal guarantees of the human rights of HIV-positive people and their families. A truly multi-sectoral response is needed, which fully addresses the diversity of causes and consequences of HIV infection. HIV is here now, and there is no more time to lose. By building on the lessons we have already learned we can save time - and lives.

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