Chapter Eight

Ripples of Change

An active involvement with the women's movement since the early 1980s had over time created a sense of arrogance and conceit within me. As gender was a cross-cutting issue, we who considered ourselves the 'gender experts' assumed we knew everything about development once we had acquired the skill of mainstreaming gender concerns in the various development sectors. A rude shock jolted me as I moved into the area of HIV/AIDS. Work on this rather 'unrecognised' sphere required a very deep understanding of sex and sexuality. It was not long before I realised how little I knew, or in fact had ever wanted to know, about this aspect of a woman's life. It seemed strange how both from within and from without there was a resistance – a feeling of bearing an illegitimate child. It required an effort and a deliberate breaking down of inhibitions. How could I be seen working with sex workers and gay men? How could I use, or even read, the rather obscene and degenerate words, be they three-lettered or four-lettered. It was quite a change from being the utopian sociologist, a part of a large movement working out details at the micro and the macro levels on how the revolution would transform the oppressed status of women, envisioning a society in which the distinctions between the 'masculine' and the 'feminine' would be eliminated. Now I was moving into working with an unknown or at best marginalised constituency of people living with stigma and shame, isolated and abused.

Any discussion with possible partners seemed so value loaded, so emotional, so culturally mediated. Searching inwards, I soon realised a secrecy, a discomfort and a denial relating to my own perceptions about my sexuality. Was I in a position to exercise good judgement in this field of HIV/AIDS? Was sexuality intertwined in my mind with morality? Was I in agreement with and was I promoting the concepts outlined by the gender-based construction of sexuality?

As I explored and as I meditated on these issues I realised that I needed to unlearn and then relearn the concepts of sex and sexuality before I could work with people living with HIV/AIDS in a manner that was meaningful and accountable. Conceit and complacence crumpled under the strain of ignorance and the rebuilding began, slowly, brick by brick, layer by layer. My education began with visits to red light areas, in India and in the Philippines, which opened my eyes to a vista of issues regarding women. These issues seemed so alien; I had not even considered them in my entire career in development work. Lessons were imparted to me over luncheon discussions with gay men in ghettos or in global conferences. Gliding through gay bars in Sydney threw up posers which I had not addressed before. I spent hours observing de-addiction processes in the drug rehabilitation centres in Myanmar, worked with people living with HIV/AIDS on quilt projects in Hong Kong and moved in the slums of Nairobi amongst shackled and dilapidated houses housing women living with HIV/AIDS. I visited women infected with the virus in the villages of Nepal. I held discussions with researchers. All this became a part of the process of rebuilding and reconstruction. Once this had been done, a search for partners began.

By the mid-1990s, the lessons learnt from the epidemic in Africa had shown that NGOs were perhaps the critical change agents in this area of HIV/AIDS. Outpatient advice and home care was the model that seemed to be delivering the greatest benefits for people affected by the epidemic. Communities needed to be mobilised and supported and in this the role

of civil society organisations was of prime importance. The reality, however, was quite different. My search for partners revealed that less than one per cent of the NGOs working on development were working on HIV/AIDS. The situation was the same in practically every country in Asia. In India in 1994, we could identify 728 NGOs working on the issue, out of over 100,000 registered NGOs. In Nepal, the figure stood at 90 of the 6000 registered civil society bodies. In the Philippines, only around 2 per cent of development NGOs were including HIV/AIDS concerns in their work. Country after country revealed a similar picture. What, then, was the future of the issue without the active participation of civil society? The future looked dismal; we needed to probe the causes of this bleak reality.

A questionnaire sent out to a number of NGOs enquiring about the reasons for this lack of interest in HIV/AIDS resulted in some interesting revelations. 'We do not want to work on the issue of HIV/AIDS because it affects very few individuals', said some NGO partners. Others remarked 'It is a health issue and NGOs dealing with health can deal with it. Why should all of us be working on it?' Yet others proclaimed 'If we work on this issue, the police will be after us – after all how can we be seen working with gay men and sex workers?' Another revelation emerged as the NGOs explained, 'We do not have the skills to work on the epidemic'. The issues raised were not only revealing, they were essentially intriguing. What were the kinds of skills required? I enquired through a series of focus group discussions in 8 countries of Asia and came to the conclusion that skills on how to talk about sex and sexuality, how to help HIV-affected households to take sound financial decisions when disease sets in and how to manage an HIV-positive person with local resources at home were some of the key issues.

The issues to be dealt with were becoming clear, as though the mist was lifting. There was misinformation in civil society regarding the HIV/AIDS virus. More than a decade into the epidemic it was still being perceived as a health issue. The epidemiology of the virus remained an

enigma to large numbers of development workers. The numbers of identified AIDS victims still continued to deceive human understanding about the magnitude of the problem. There was a need to shift the focus of understanding of the epidemic from the 'individual' to the 'community', as risk-associated behaviours such as unprotected sexual intercourse or sharing equipment among injecting drug users were largely seen as individually not socially driven.

With these challenges, a pilot initiative in India, entitled 'Strengthening Community Based Responses to HIV/AIDS in India', was launched. The history of this project dates back to 1995, when a situational and needs assessment of NGOs in India in relation to the epidemic was conducted. The report drew attention to the need for increasing partnership between government and NGOs and also to the need for capacity building among NGOs. This was critical to expand the response to the epidemic. The situation and needs assessment also clearly revealed that 80 per cent of the funds channelled through NGOs had been used for awareness-building and condom promotion programmes for over half a decade and yet there was little evidence of any kind of behavioural change among the communities. It was clear that the approaches adopted had relied on the assumption that the fundamental problem to be addressed was one of lack of knowledge and that the provision of information in itself would lead to a change of behaviour.

Hence, drawing upon the experience of other health and development issues such as population and reproductive health, countries had invested in large-scale 'IEC' campaigns, sometimes in combination with more focused educational campaigns for specific susceptible groups. The large-scale nature of these activities resulted in content which tended to be general, rather than specific, simple, rather than complex, and externally determined, rather than locally generated. Not surprisingly, the impact evaluation of these efforts consistently revealed significant potential in terms of creating changes in awareness but much less convincing

evidence to demonstrate impact on behaviour.

Another broad conclusion was that the risk of HIV associated with behaviour was 'social' in nature, involving more than one person and occurring within specific social, cultural and economic settings. An enhanced understanding of the socio-economic causes and consequences of the epidemic among the community was necessary to reduce risk behaviour within both social and economic contextual realities.

By 1996, many NGOs in India, frustrated over the lack of effectiveness of IEC and awareness-raising campaigns, were willing to explore alternative educational approaches based on participatory principles which could sustain the learning process and render it more useful in creating capacities to prevent the spread of HIV/AIDS in the country. As Prakriti, an NGO in India, put it: 'To make people accept their vulnerability, acceptance has to come from within themselves. Time and time again, an empathetic non-judgmental democratic approach has worked where no amount of top down teaching has succeeded.'

In an environment that was receptive, the charming and convincing Lyra Srinivasan partnered us in our efforts and visited a number of NGOs. During 1996–97 attention was drawn to the potential of participatory approaches in influencing human behaviour by enhancing understanding about HIV/AIDS in India. In her subtle, unassuming yet persuasive style, Lyra developed and demonstrated to a group of NGOs a number of participatory learning tools of relevance to the epidemic. Above all, she explained the principles of participatory learning.

The first and the foremost tenet was respect for the individual as an adult with experience, ideas and concerns of his/her own. In line with this principle, substantive content is not imposed on adults but opportunities are provided for them first to tap their own rich experience and then to identify issues and situations requiring further analysis. They are thus participants in a process in which, in lieu of an instructor, there is a facilitator who encourages group participation, and learns much more from

the group's sharing of experience. To ensure that this happens, the facilitator avoids beginning the session with a lecture, but instead engages the participants with a task which they can all freely engage in. This may include defining their own ground rules on attendance and participation in the sessions.

The second tenet was ensuring an enabling environment in which the participants felt comfortable in expressing their ideas and in supporting or challenging each other if they so wished. This is particularly important in a sector such as HIV where sensitive issues are likely to come up concerning sex and sexuality, stigma, gender power relations, blame and hostility, personal income losses, family crisis and pain. To create and maintain this type of enabling environment, in which all the participants can feel safe in being open and honest, the facilitator makes sure that all vestiges of hierarchical relationships are removed. This applies even to the room arrangement and to the positioning of tables and chairs, thus allowing the participants to move around and constitute sub-groups of different sizes more easily than if they were all facing a head table as the focus of control.

The third tenet was the use of non-conventional discussion media, i.e. pictures, cut-out figures, 'chits', props or other aids which the participants themselves can manipulate, sort out, prioritise, modify and interpret as they wish. This is another means of equalising communication opportunities and helping to uncover talents within the group which might otherwise not be disclosed in a more formal stratified set-up. The tools give all members of the group a chance to be involved in some way since, for example, it takes many different talents to create a mural, take part in role playing, or actively engage in group problem-solving. The aids also help to liven up the session, providing scope for creativity, analysis, planning and sometimes even humour.

The informal consultation led to the organisation of a training workshop for NGO representatives on HIV and development. The informal

consultation enriched a group of NGOs working on HIV/AIDS issues in India with concepts relating to participatory approaches and the HIV and development workshop provided information on the socio-economic causes and consequences of the epidemic to a large group of NGOs in the country who have been working on participatory approaches for over a decade but not essentially on the epidemic. This suddenly expanded the pool of partners in India who could work effectively on the epidemic with an in-depth understanding about HIV/AIDS using participatory methods and approaches.

I could actually feel the expanding ripples as I prepared for the HIV and development workshop for our NGO partners in India. The process had begun; the smaller ripples were now producing larger ripples. The interest in the issue was overwhelming. I sat there in the conference room struck with amazement and wonder. These were the very NGOs who had categorically informed me not too long ago that HIV/AIDS was not that important a development concern and asked 'Why should all of us be working on it?' And yet the use of participatory methodologies as learning tools had generated a unique interest and commitment in the same group of our partners. With barely a skeletal support from donor agencies, amounting to just $400, driven by motivation, the NGOs took over the process to expand the ripples. Similar workshops were organised in 7 states of the country, not by facilitators recruited by the donors, but by the NGOs themselves. These events soon galvanised the creation of a planning group for the initiative within the country. This planning group was composed of 8–10 umbrella NGOs who became the driving force for the effort as more and more trainers were oriented in the use of participatory learning tools.

The tools were exciting and innovative but, above all, were prepared and owned by the planning team. The tool entitled 'Sex and Sexuality' imparted the much-needed skill of how to talk about sex and sexuality. Coupled in pairs, the participants discussed the most intimate part of their

lives as they responded to the following key questions:

- Recall the first time you heard the word 'sex'. How old were you and how did you feel about discussing the subject?
- Recall the first time you asked someone about sex and under what circumstances?
- Have you ever seen yourself naked in front of a mirror? What were your feelings about your body?

And as they completed their conversation with the facilitator, freely expressing their views, further reflection was provoked by issues like 'what sexual information do you still lack today?'

The learning tools used were amazing

Whether it was the 'Fleet of Hope' or the 'Story of Maya' or the 'unserialised posters', the training sessions stimulated very active lighthearted and non-confrontational discussions. The 'Women's Balloon Exercise' promoted group reflection on the many interrelated factors which determine the impact of HIV/AIDS.

Discussions were held on women's wellbeing and productivity, and on ways of empowering them to play an optional role in the epidemic's collective prevention and support effort. Perhaps the tools that evoked maximum interest and fascination were the 'Demographic Silhouettes'. Through multiple sets of cardboard cut-outs, silhouette figures of men, women and children representing 9 different age groups, an awareness was generated about the gender-focused causes and consequences of HIV/AIDS. In the spirit of participation and acknowledgement of the pool of learning available in the country, Lyra had remarked, 'these tools are not perfect and were never intended to be. They can only be sharpened and perfected through experience. Each try out brings new insights and points to more exciting possibilities. Questions will always provoke

healthy inquiry, why use three discussion groups instead of two or even one? Do discussions in a lighter vein tend to belittle the seriousness of the issues arising from the epidemic? Questions of this kind and more await experimentation and feedback by trainers everywhere. The only requirement is that they take the time to document and share the insights they acquire in the process.'

Lyra's words ring true. Today, in 6 states of India, NGOs have framed dynamic action plans strengthening their counterparts in the government, in civil society and in other training bodies with these techniques. The initiative is no longer a capacity development effort, it has acquired the status of a movement. Larger issues relating to government–NGO partnership in preventing the spread of HIV/AIDS are being discussed and debated. Release of funds in support of the proposed action plans when it is being processed in large bureaucratic set-ups, be they national or international bodies, has taken time. But the work goes on.

Looking back at the series of events that culminated in the training of trainers and the formulation of state action plans to expand the community-based response to the epidemic, the entire process seems long, tedious and cumbersome. Perhaps this was so because we chose the consultative processes over top down approaches. Cajoling, convincing, encouraging our partners has not been easy. Moving away from IEC approaches to mobilisation for social change has taken its toll of individual capacities in spite of this tradition being particularly rich in India. But what I keep asking myself as I write is: 'Could it have been any way other than this?'

The initiative is not devoid of problems and dilemmas. Government support for this initiative has been surprisingly low. It is often said that the forces that actively work towards protecting the status quo resist any attempt to bring about systemic changes. However there are examples where strong and dynamic leaders in organisations have been able to make a beginning. It all depends on our ability to build a strong pressure

group to force the leadership to acknowledge the need for change in order to achieve its own stated objectives. The processes set in motion have created ripples of change. We hope that the tools prepared and disseminated will empower the disempowered to not only analyse and express their reality but, as Robert Chambers has said, ' to put the reality first'. Unless this is done the epidemic is on track to dwarf all other catastrophes.