

# Struggles for rights, equity, power

Dominique D'Souza's words, "I live in the hope of a world if not free of disease, free from fear and discrimination" remain the most powerful message even today.



*Shobha Raghuram*  
Director of the India Regional Office of the Humanist Institute for Cooperation with Developing Countries (Hivos)  
Bangalore, India  
[s.raghuram@hivos-india.org](mailto:s.raghuram@hivos-india.org)

## The stigma syndrome in India

In a country where more than 400 million people are living in poverty, unable to access health care, decent work, acceptable quality of life standards and severe gender discrimination HIV/AIDS poses serious challenges for state, health providers, private aid organisations and civil society associations. When the first HIV/AIDS case was officially recorded in India in 1986, voluntary organisations, policy makers and those concerned in government were faced with a situation where millions of the poor had little access to free public health care.

Mainstreaming HIV/AIDS connected issues in broader development debates and interventions, creating an enabling environment for people living with HIV/AIDS became overnight dominant concerns. The stigma syndrome associated with HIV/AIDS was reminiscent to many public health specialists of the decades during the 50s and the 60s when leprosy was socially considered an 'unacceptable' illness. Since then, the climate in the country has changed considerably, thanks mainly to the efforts of strong associations of people at the grassroots who have mobilised community organisations of affected people and launched a consistent attack on conservative and repressive responses to the illness by the publics and by medical organisations.

## Hivos initiatives

Hivos was one of the first development organisations in India to support civil society organisations in 1992. South India AIDS Action Programme (SIAAP) in Chennai focused on grassroots participation for protection of human rights as well as HIV prevention. Positive People in Goa were inspired by the founder, the late Dominique D'Souza who moved thousands in the

country with his relentless campaigning for the rights and the dignity of people living with HIV/AIDS (PLHAs). His words, "I live in the hope of a world if not free of disease, free from fear and discrimination" remain the most powerful message even today. Lobby advocacy, counseling services, help lines, capacity building of fledgling community organisations, development of training curricula, support for the struggle of sex workers to overcome their vulnerability, strengthening organisational capacities; these are the wide range of civil society interventions Hivos supports among its partner organisations.

Studies in the country have shown that almost 70% of poor household incomes are spent on health. Persistent poverty therefore is a reality for the vulnerable - one ill health episode forces a poor household just above the poverty line to sink again. In such a context, access to HIV/AIDS treatment, remaining in the workforce, being a member of a supportive community, overcoming predominantly gender bias in social life are difficult challenges for affected people. However, HIV/AIDS cuts across caste, class and gender, making issues of redressal far more complex e.g., people living with impairments, people with alternative sexualities, and children are some of the constituencies which require distinct sets of policies and services. The common thread that unifies everyone is the persistent 'vein' of discrimination which is not only a major deterrent to progressive rights and access to treatment measures, but a major source of the erosion of subject-hood for those affected and for families and support groups.

HIV prevalence (among the people of the age group 15-49) in 2003 was at 0.4-1.3%. Given demographically a very young population, these percentages represent a sizeable population of the affected in a

## Freedom Foundation activities against HIV/AIDS

Established in 1992, the Freedom Foundation was initially started to provide an effective treatment programme for alcoholics and drug-addicts. Freedom Foundation works in the fields of Alcoholism/Drug addiction and AIDS. In 1995, it took up the issue of AIDS when a link was noticed between addiction and AIDS. The organisation, also works in the community, educating villagers about AIDS and the spread of this disease. They also have corporate sessions to train those in business or industry on how best to deal with employees affected by AIDS.

It has opened a rehabilitation centre for HIV positive people, the first of its kind in the country. In December 2000, a second de-addiction centre was opened in Hyderabad. Another two HIV/AIDS Care and Support facilities have been started, one at Hyderabad and another at Bellary, where the incidence of HIV is high. A Project to rehabilitate sex workers at Siruguppa, near Bellary, Karnataka State is running since June 2001.

Source: <http://www.thefreedomfoundation.org/index.html>

country of a billion population. Altogether six organisations and a major coalition apart from two organisations with HIV/AIDS related work are supported by Hivos. However, all these organisations are extensively linked to community organisations, social movements, lobby groups, and national and international networks. Many of them are members of government review committees. Therefore, their social base is fairly wide and extensive, vertically connected to major institutions in the country as well as horizontally linked through shared work and common goals. They have been instrumental along with other organisations in:

- forcing in public policy changes in the perception of HIV/AIDS
- extensive training of sex-workers, sexual minorities, the physically challenged, and establishment of counseling centres
- reform of local bodies, public medical hospitals, educational institutions and other service institutions for equity access for HIV positive people
- collectivisation efforts at the field level communities of the affected so that critical mass build up can occur and sea changes can be brought about in the arena of rights and entitlements.

### Challenges ahead

The major challenges ahead for all organisations include the following:

- 1) Education - spread of accurate and clear information about the illness in all local languages.
- 2) Solidarity among all organisations in the country regarding issues of access, rights, subject-hood of the affected collectivisations and coping strategies.
- 3) Assisting people to decode the language of discrimination sufficiently enough that feelings of guilt, denial, anger and loss may be channeled into developing collective strategies of strength, faith, and constructive engagement. This will provide hope and possibilities for people who are not only affected but to everyone who is committed to seeing a world more equal structurally and more elevated by the gaze of respect and dignity for the other.
- 4) Broader social security issues and workplace policies for HIV/AIDS.

### Conclusion

Ultimately the phenomenon of HIV/AIDS has forced a world to recognise that development goals are both material and non-material.

The vulnerability of others must be seriously understood so that more strength across borders of community, language, culture may be further built. The strength of millions coping with this problem and the losses must be learnt and celebrated. Millions in Africa have witnessed the loss of close ones in their homes, their workplace, their villages, their towns, in their governments and in all institutions (both public and private). The story of missing generations has added to a record of global failures in development commitments and generation of interventions. The state has to take cognizance of these realities, learn from them and work with civil society organisations to stem the tide and overturn the discourse of discrimination, loss of livelihoods, and denials. Commitment is needed for both HIV/AIDS as a critical aspect of development policies and interventions as well as HIV/AIDS as an issue in itself which requires specialised dialogues of intervention and organisation of people and reform of institutions. ■

The complete article with references can be read at [www.i4d.csdmns.in](http://www.i4d.csdmns.in)

### Mobile Games on HIV/AIDS Awareness

ZMQ Software Systems, an eLearning, gaming and edutainment solutions company, based in Delhi, has launched 4 Mobile Games on HIV/AIDS Awareness on the World AIDS Day 2005. While the games premiere on December 1 on Reliance Infocomm's R-World, other operators will be subsequently releasing the games by the end of this year. On International Labour's Day, 1st May 2006, ZMQ will launch these games globally, converting the content and language compatible to regions of Africa, South East Asia, Central Asia and Latin America. For further information, contact at [zmq@vsnl.com](mailto:zmq@vsnl.com)



Source: <http://www.freedomhiv aids.in/>