

# **NATIONAL CONSULTATION ON HIV/AIDS AND THE MEDIA**

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**UNDP HIV & Development Project  
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## Foreword

Media can play a vital role in disseminating accurate information on HIV/AIDS and guide the attitudes of people towards a sensitive approach to those affected by the epidemic. It is a key player in moulding public opinion and debate on issues that need attention.

There is an urgent need in South Asia for informed media coverage of critical HIV and Development issues that recognizes the importance of the people infected and affected by HIV and moves away from sensational reporting. This requires that the media's (both the press and the electronic) understanding and knowledge of the epidemic and the sensitivities associated are strengthened.

In the past year, the UNDP Regional HIV and Development Programme initiated a process of consultations with key partners on the above subject. Subsequently, important media players were brought together in various participating countries with the objective of creating a regional network of committed and sensitized media people. Attention was given to facilitating objective, sensitive and informed reporting on issues related to HIV, Gender and Rights issues.

National level media consultations have been initiated in six countries, namely: India, Bangladesh, Nepal, Bhutan, Pakistan and Sri Lanka. Partners include, Rotary Dhaka, Centre for Advocacy and Research, Nepal Press Institute, Bhutan Broadcasting Service and Kuensel, Alliance Lanka with other media partners and Pakistan Aids Prevention Society & UKS. These national level consultations will feed into a regional level workshop with journalists and media people from the six participating countries.

They will explore ways to develop a functional media network that will not only create guidelines for sensitive reporting on issues around HIV but also generate a deeper understanding of the development implications of the epidemic in the South Asian region. The network will work as a facilitator for journalists in the region to build capacity in both the quality of their reporting as well as in getting access to better and more accurate information on the issues.

This is the report of the country consultation in India.

Sonam Yangchen Rana,  
Regional Programme Co-ordinator,  
UNDP HIV and Development Project  
for South and Southwest Asia

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# NATIONAL CONSULTATION ON HIV/AIDS AND THE MEDIA

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## Introduction

The numbers of those affected by HIV/AIDS is growing across the world. In India, the number has crossed 3.7 million. This has serious implications for human development, human rights and the economies of individuals, families and nations.

Prompted by these concerns, the United Nations General Assembly convened a special session in June 2001 to set goals that would enable countries and governments across the world to address the many ramifications of the epidemic.

It was in the run up to this special session, and as part of the regional media initiative in six countries in South Asia, that this National Media Consultation was organized by UNDP HIV & Development Project for South & Southwest Asia in collaboration with the Centre for Advocacy and Research (CFAR), New Delhi. The consultation was primarily aimed at providing a forum for media practitioners, experts, advocacy groups and those living with HIV to reflect on the media's response to the epidemic and the development issues around it.

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## Issues before the Consultation

- Has there been sufficient reflection on such related issues as the economics and politics of funding, general public attitudes, social responses and cultural points of view and perspectives?
- Is HIV/AIDS a matter of politics and deep-rooted social inequities (especially gender discrimination), apart from being a health issue?
- What are the state level and national level policies that impact on the spread of the epidemic?
- What opportunities does the media have to partner with governments, NGOs and community based organizations to strengthen response to the HIV epidemic?
- Does the media's preoccupation with a certain kind of journalism deter us from bringing these issues to centre stage?

## Objectives

The daylong consultation focussed on the perceptions of the media practitioners with regard to the epidemic, and the challenges they faced while dealing with the issue. Additionally the consultations attempted to:

- Evolve an internal consensus of what needs to be advocated and what could be done to expand and further the Media's engagement with HIV/AIDS.
- Promote and develop partnerships, and support the efforts of the government, NGOs and those living with the virus.

- Motivate the Media to continuously disseminate information on the issue.
- Link the concern with development-related issues that affect a cross-section of society, especially vulnerable groups like women, sexual minorities, victims of trafficking, children, sex workers, migrant workers etc.
- Develop a more proactive role for communicators as watchdogs and catalysts of development.
- Develop a network that will collaborate at the regional level.
- Evolve guidelines for the Media.

## Participants

- Participants included editors and senior media practitioners with a proven track record of covering HIV/AIDS and related issues from both, the print and the electronic media. Some of the key speakers were Ms Nirmala Lakshman, Joint Editor, *The Hindu*; Mr. D.N.Bezboruah, Editor, *The Sentinel*; Ms Sathya Saran, Editor, *Femina*; Mr.Chandan Mitra, Editor, *The Pioneer*, and others. (See annexure).
- In view of their varying levels of interest, initiative and commitment to the issue, some of them were requested to make brief presentations on aspects of the issue that they had been focusing on.
- Sharing of experiences by people living with HIV/AIDS: The Indian Network for People Living with HIV/AIDS (INP+) and the Manipur Network of People Living with HIV/AIDS (MNP+) were invited to make presentations based on their experiences with the media. INP+ undertook a broad audit of HIV/AIDS reportings by the national media from the perspective of people living with the virus and presented the findings. CFAR provided them with samples of reports, features, and editorials from the national Press, including some from the Tamil Press. MNP+ elaborated on regional implications of the issue from the perspective of positive people.
- As the coordinator for the consultation, CFAR made a qualitative assessment of the Media's response to HIV/AIDS based on reports over a period of six months.

## Experts

Dr. Swarup Sarkar, Inter-country Technical Advisor - UNAIDS (South Asia Region) and Ms. Beverly Brar from UNDP, South and Southwest Asia regional project were invited to make presentations on the developmental aspects of the issue.

## Format

The consultation comprised of three sessions:

### The Inaugural Session

- ***Taking stock of HIV/AIDS – Role of Editors*** – Presentations were made on the experiences of people living with HIV/AIDS, and the perceptions of Media practitioners, so as to get an overview of the issues surrounding the epidemic.
- Positive networks cited examples from media coverage of the issue and shared their concerns on how society, including the Media, was responding to the situation.
- CFAR provided an assessment of Media coverage of the issue.

- Editors spoke of the challenges they faced while dealing with the problem. They initiated a debate to ascertain how they could respond to the issue.
- Experts spoke on what an epidemic of this magnitude meant to the nation in terms of health and development.

### **The Second Session**

**Sharing experiences** provided the media with an opportunity to express their points of view, and share their own experiences on working in the field on the issues around HIV.

- Senior media practitioners made presentations on how their publications were addressing the issue of HIV/AIDS and the development concerns around it
- An open discussion was conducted on some of the journalists' own experiences while reporting and writing about the epidemic.

### **The Concluding Session**

#### ***Developing guidelines and norms***

This session allowed for some concerted group work towards developing norms and guidelines that the media could (and should) follow while dealing with this sensitive issue.

#### **Expected outcomes**

- Increased awareness and a heightening of sensitivities among media practitioners.
- Partnerships between the Media, positive groups, and those interested in widening their understanding of the issue and its linkages with various aspects of development and human rights.
- A set of guidelines that can be used as a basis for evolving a self-governing mechanism within the Media vis-a-vis the sensitivities surrounding the issue of HIV/AIDS.

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## **Prioritizing HIV/AIDS: The Challenges Ahead**

### **Setting the agenda**

HIV/AIDS is spreading at an alarming rate all over the country. Over the next decade, the HIV virus is likely to be the biggest cause of death amongst India's adult population. Urgent action is required if the impact of the epidemic has to be minimized.

Infection by the virus is preventable, and the spread of the epidemic can be stemmed if prevention strategies are put into action on a large scale. There are strong linkages between incidence of infection and the economic and sociological vulnerability of specific groups; and there is ample evidence that those who have information and choices can protect themselves from exposure to the virus. But efforts to address the more vulnerable sections of society - young migrant men who are away from home and separated from their regular sexual partners, for example, or women and girls who have been trafficked into sex work - have been inadequate. Women are more vulnerable due to biological reasons, and also because they often have little control over their sexual lives within our socioeconomic context.

Experts also opine that merely providing information about the problem will not suffice, especially among people who are struggling for survival on a daily basis. For awareness-building exercises

to succeed, they must be part and parcel of a multi-pronged strategy towards creating an enabling environment and empowering people, so that knowledge about the virus can translate into safe behavioral practices.

### **Reaching the vulnerable**

A serious look at prevention efforts reveals that coverage of vulnerable populations continues to be inadequate. Even in high incidence states only 25% of sex workers are reached. It is interesting to note that it took five years for planners to realize that it is the client who decides condom use, and that sex workers must be empowered to insist on condom use if it is to be a tool in HIV/AIDS prevention programs. Similarly, much more must be done to address the estimated 250 million young people and migrant workers who will be affected in the fourth wave of the epidemic. Unfortunately, the burden of creating awareness among such groups has been largely left to small NGOs and peer educators. This task needs to be taken up by Governments of the region with the urgency that it deserves.

### **Commitment to investment**

The levels of political will required for dealing with the problem are falling far short of what is required to effectively combat the epidemic. There is also a need for larger investments towards the prevention and management of the epidemic. Thailand, which has had great success in combating the virus, spends US\$1.3 per capita. India, in comparison spends just 60 cents per capita. A debate on resource requirements and resources utilization has also become necessary, because it has been noticed that donors are not always aware of how much is needed. This has resulted in a vicious cycle of under-funding and under-spending.

### **Raising awareness to enhance the coping process**

Media and society must provide greater support for awareness programs, and must help in generating conditions within which people are empowered to protect themselves from infection, and the affected are empowered to live with dignity in society. Strategies must also be formulated to remove the stigma that is presently attached to the virus. Stigma prevents any kind of open social discussion regarding the issues surrounding HIV/AIDS; and this in turn affects prevention programs and drives the epidemic underground. Further, it prevents positive people from seeking care and support services. An enabling environment would make it possible for NGOs and others working with marginal groups like sexual minorities, sex workers, and drug users to conduct their interventions without being misunderstood.

### **Concerns of people living with and affected by HIV/AIDS**

One of the principal concerns of respondents to the survey done by INP+ was that prevention programs had not really taken off despite all the effort and money spent over the past fifteen years on awareness programs. It was also felt that many myth and fallacies were the result of inappropriate awareness campaigns and sensationalized reports in the Media. At times, reports are exaggerated and in violation of the rights of people living with the problem. Pseudonyms, for instance, were sometimes used for the sake of confidentiality; but no accompanying clarifications were given, resulting in misunderstandings. More importantly, it makes people living with the problem wary of interacting with the Media.

On the other hand, it has also been noticed that myths were broken after people living with HIV/AIDS spoke to the press about their lives. Such testimonies, it was noted, provided insights to the general public of their problems. It has also helped the general public to realize that people affected by the problem are not patients confined to their beds, and that there is a positive side to HIV/AIDS - a life beyond the virus, as it were. Moreover, such interactions have gone a long way in building trust between the Media and people living with HIV/AIDS. They now feel they have allies in the Media who will report their concerns and make the general public realize that the

issue is not just about indices of infection, but also about human lives, individuals and families. Unfortunately, such reports have been few and far between.

### **Perils of insensitive reporting**

Respondents were distressed by some of the reports in the media which revealed names and other details of those who had been infected by the virus. They felt that this sort of sensationalized reporting resulted in paranoia, rather than empathy amongst people; and prevented infected individuals from revealing their status for fear of discrimination and the loss of what little support they had.

Some respondents even felt that the reports were false, while others were of the opinion that the Media deliberately sensationalized reports and added “*masala*” to increase the popularity of their publications. This was chiefly because there were huge gaps between the way in which an incident occurred, and the way in which it was reported. In one instance, a woman’s house was burnt in a property dispute but Media reports stated that it was on account of her HIV+ status. Respondents did, however, note that at a different level they sympathized with the people featured in such reports and felt a sense of bonding with them.

One consequence of the stigma surrounding HIV/AIDS is that most people avoid testing and are therefore unaware of their status. Yet, it was noted that neither the government nor any NGO is doing enough to persuade people to take the test. It was also felt that the Media could do more vis-à-vis the issue of treatment, because the reports that have appeared were primarily on what drug companies like CIPLA were doing. Why, it was asked, was no one questioning CIPLA’s decision to lower the cost of its drugs; or its moves to force the government to issue it with a compulsory license? And how would any of this benefit people living with HIV/AIDS..

It was also felt that journalists required more expertise on this issue because there was a tendency to use wrong terminology for the affected: For instance, the usage of the terms “terminally ill” or “AIDS patient”. The media, it seemed to the participants, was unaware of the fact that HIV/AIDS does not create a constant state of ill health; and that when infected persons are well their production levels are on par with everyone else. Unfortunately, the Media tends to portray the infected individual as terminally ill and on the verge of death, resulting in pity and fear rather than genuine empathy. The statistics they use are also often outdated. For instance, 1998 figures are quoted in a report written in 2001.

### **How do people affected by HIV/AIDS want the media to respond**

- **Advocate the rights of people** living with the epidemic.
- **Refrain from sensationalizing reports** because it only creates a lot of negativity on all sides.
- **Maintain confidentiality:** Failure of the Media and the medical fraternity to do so was creating fears among the general public and turning them off the problem when in fact they should be motivating them to provide a more supportive role and participate in mainstream prevention programs.
- **Avoid understatements and inappropriate terminology.**
- **Update** their information.
- **Research** their stories.
- **Go beyond the news imperatives** in their reports and explain the human dimensions of the issue.

- **Build partnerships** with those affected by the epidemic. This would give the media a better insight into the concerns and problems of the affected, and go a long way towards altering the prevailing scenario of stigma, discrimination and distrust.

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## Media Coverage: A Defining Role

### Thematic or sustained coverage?

Media coverage of the epidemic falls short of the expectations of the positive groups for failing to focus on their needs and concerns, rather than the epidemic per se. But CFAR's monitoring revealed that the Media were neither ignoring the issue nor marginalizing it; and that everybody was doing their bit to raise awareness and focus on stigma and discrimination. The Media, moreover, were playing a definitive role in instilling a sense of immediacy, commitment and responsibility that was not there previously.

For instance, in the run up to campaign days like World AIDS Day (and for some duration following it) there was a substantial increase in coverage in both the English and the Language press. Partly this was on account of the increased number of press releases reaching them; but anywhere between 25 to 50% comprised in-depth features on a whole gamut of issues relating to the epidemic, including human rights and access to care. In fact, there were numerous well-written and compelling stories on the stigma and discrimination surrounding the epidemic, especially in rural areas; and its effect on such vulnerable groups as women, children, prisoners and sexual minorities.

Similarly, in a sample survey of the month of March 2001 (when there were no major events) the issue got fairly extensive coverage because there were numerous time pegs. NACO (National AIDS Control Organization) had just released its surveillance data, and there were several awareness drives in various parts of the country. There were also numerous reports on government allocations for HIV/AIDS and the reactions of state governments and State AIDS Control Associations regarding the allocations.

### Influencing policy

In fact, a qualitative assessment revealed that the Media played a significant role in influencing developments on such vital issues as the CIPLA drug controversy and the policy decision taken to provide free treatment across the country to halt vertical transmission from mothers to their unborn children. Similarly, there were numerous well-researched articles on various aspects of the CIPLA controversy vis-à-vis patent laws, WTO, the TRIPS Agreement etc. What was particularly heartening was that though this is a complex and complicated issue, the Media did not compromise on the quality of coverage or information that it put out.

### Reshaping coverage

What was noticed during the assessment was the urgent need to reshape the norms of coverage, particularly in the print Media, to ensure consistent reportage on the issue of HIV/AIDS. Quite clearly conventional newsgathering processes inhabit the kind of well-investigated, well-informed reports that an issue of this dimension requires. Also, editors do need to invest in highly specialized reporting to create reports that take into account the various facets of the problem, and contextualize the whole situation. People must be taken into confidence and the media needs to engage in the sort of civic journalism the issue calls for. The media must involve itself deeply in the issue in order to become a part of the solution. This is imperative because development and other serious issues are increasingly getting nudged out in terms of space by glamour and

entertainment. And it is not just a question of column space but of quality reports: A well-written, well-informed report is invariably remembered, and has high recall value.

The tendency to string together disparate voices and unrelated experiences when each of them may merit separate investigations is also of concern. Moreover, no purpose is served by this sort of opportunistic juxtapositioning of information because it fails in its basic purpose: To inform people, so as to enable them to take relevant decisions regarding their lives and their behavior. Yet another failing is the tendency of the Media to become self-opinionated, to put itself in the context and knit together disparate issues and give itself an arbitrating or mediating role.

(See details of mapping in appendix)

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## **Editors Reflect<sup>1</sup>**

### **Creating a Responsive Media**

The principal concern raised by the Editors was on whether enough was being done by the Media to reflect general public attitudes, social responses, cultural points of view and deep-rooted social inequities, especially that of gender discrimination. The feeling across the board was that while “the Media was trying to do its best, the job was imperfect in many ways”.

### **Setting ethical norms and standards**

Editors agreed that the charges made against the Media – of being false, inaccurate, uninformed and insensitive in its reporting of this sensitive issue - “were indeed valid.” In fact, the editors felt that reporting on HIV/AIDS had been reduced to a mere ritual, as has been the case with many other developmental campaigns. It was their opinion that more effort was needed to do away with the mental blocks people have on this issue, in order to involve them with the problem.

The editors also felt that the Media should take an active role in creating awareness, and in evincing a kind of social justice as far as the handling and reporting of HIV/AIDS was concerned. Moreover, as Mr. Bezboruah said, “reports should be positive, correct and sensitive. (They should have) the kind of reporting that reflects ... feeling behind it.”

Unfortunately, there is an element of schizophrenia in reporting HIV/AIDS, especially in the language press. At times there is excellent reportage on the issue; but at other times it gets reported in an unsympathetic manner, through the lens of a certain middle-class morality that generates sensationalized, horrific accounts. There was a broad consensus that the preponderance of market forces in determining what people watch, and what they want to read, was coming in the way of issues like HIV/AIDS being presented with the seriousness and the space they required.

### **Approach to coverage**

The editors stressed that not enough effort was being made to get to the bottom of the problem and discuss issues in-depth. Also, the inadequate realization of the seriousness of the epidemic was of concern, as it results in the creation of stereotypes and symbols. The focus, it was felt, should be on the human dimension of the problem; on taking up individual case studies and looking at the epidemic through the eyes of those affected by it. Such an approach would undoubtedly have an impact on people, especially if done on television.

They felt that even small successes in the fight against the virus should be played up to motivate people, and also that the Indian language newspapers and publications should be sensitized to the issue and involved in awareness-building campaigns. This, they felt, was crucial - especially with regard to the larger issues of poverty and ignorance - because of the access these publications have to the lesser-privileged and more vulnerable sections of society. It was also suggested that every effort should be made to provide accurate information, with no bias against

any community or way of life. Facts should be checked and rechecked for accuracy; and there should be no sensationalism.

More importantly, reporters should respect the privacy and human rights of the affected. They should put themselves in the place of the affected so as to remove the divide between them because empathy, as Ms. Sathya Saran noted, is important: In her words: “Empathy lights another lamp of empathy; and another; and can, in time, alter public opinion.”

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## Practitioners’ Point-of-view

### Questioning attitudes

The overall consensus was that the Indian Media needs to question the nation’s response to HIV/AIDS. Rupa Chinai, who has been focusing on the epidemic from its early years, thought that the issue of HIV/AIDS was not being examined in its entirety; particularly in the context of less privileged communities where poverty, poor nutrition antibiotic and recreational drug abuse are perhaps contributing to immune-suppression.

Additional points in question was the focus on clean needle exchange programs, rather than on detoxification and rehabilitation; the practice of putting drug users through ‘cold turkey’ withdrawal techniques when there are opiates that can ease the procedure and whether these were practical and feasible long term strategies. Concerns were also raised regarding the numerous incidents of wrong testing that have come to light. The fact that poor testing and surveillance facilities make it difficult to isolate cause of death which often gets registered as TB or Malaria rather than HIV/AIDS

The non-availability of updated data on the epidemic was also the subject of much debate; as was the fact that most people go in for just one test, when WHO requires three tests to be conducted before confirming positivity. The failure of the Media and the pharmaceutical industry to inform people of the high toxic levels of drugs prescribed to those who test positive was pointed out; as also the fact that only a few media persons were actually speaking up on the issue of HIV/AIDS.

### Looking at the larger picture

Pramod Kumar saw HIV/AIDS “as a symptom of a larger issue”, one that goes beyond health to include deprivation, marginalization, inequities and vulnerability. He described it as a classic epidemic despite inadequate data; an epidemic that is claiming lives and families, and calls for compassion, sustained advocacy and a paradigm shift in thinking. He felt the entire HIV/AIDS questions should be seen in the wider context of a development issue.

It was also felt that, in many ways, the issue, had proved to be a blessing in disguise: The issue of HIV/AIDS has provided journalists with opportunities to write on social inequities and taboo subjects such as alternate sexuality and the sexual exploitation of children. It has also brought to light the commendable contributions of people, their enormous commitment, resilience and will. The Media, it was felt, could do a great deal in terms of advocacy by interacting with and helping those living with the problem; and by taking the epidemic out of specialized discussions and into mainstream journalism.

### Questioning “best practices”

Oindrila Mukherjee, who has been closely watching the progress of Kolkata’s Sonagachi Project felt that the project - hailed as a prototype that should be replicated in red light districts in other

cities - begs several questions. For one, is the prevailing focus on awareness and empowerment a disguise for the failures and limitations in the implementation of its condom promotion program? For another, are the statistics that are being touted reliable, considering no external evaluation is possible? As a corollary, even if they are reliable are they good enough given the expenditure and fund allocation? Even the project's own evaluation cites the frequent occurrence of STD and high rates of pregnancies and abortions among sex workers due to their failure to use condoms.

Given this example, she felt it was important for journalists to arm themselves with accurate figures and ground realities before recommending prototypes, policies and solutions.

### **Sensitizing the electronic media**

The feeling among participants from the electronic media was that there was an urgent need for guidelines and for the sensitization and re-training of those in the electronic media vis-à-vis the epidemic. Channels, especially regional channels, were paying scant regard to the privacy of those affected by HIV/AIDS. Photographs of the affected are flashed across screens and personal details are reported. Much of this may have been done in good faith in the misguided hope that this will enable them to get help from somewhere; but what of the social stigma that these individuals have subsequently had to live with?

On the question of credibility, participants voiced concerns regarding the technique of reporting a story where both visuals and sound bytes could be construed as violating the privacy of the interviewed individuals. Journalists also stressed that credible sources of information were few in number: Whose words could one trust?

It was suggested that the government be sensitized to share information so that the Media as a whole could deal with this issue.

### **Inadequate coverage**

Referring specifically to the Indian language press, a senior correspondent and author of a book on HIV/AIDS pointed out how persistent coverage could – and did - promote reader interest. He spoke from his own experience of how, in the late 1980s, articles on the epidemic would get no reader response at all. In comparison, he felt the volume of response and the queries now being generated (especially from rural areas of Maharashtra) was almost alarming.

Yet few in the decision-making echelons of Media organizations seem to realize that there is a social dimension to the issue. So, while health stories almost always find place, HIV/AIDS is rarely featured. A participant wondered if this was because no one was talking about it at an official level; or whether it was because the Media's concerns and priorities do not place a high premium on development.

Uganda was quoted as an example for positive intervention by the media, where certain districts successfully brought down the HIV prevalence rate from 25 % to between 6 and 8% with support from the Media. The focus there was on asking young people to use condoms, to delay their first sexual contact, and to restrict their number of sexual partners. The Media backed the campaign up by informing the general public of the advantages of monogamy, the importance of counseling etc.

### **Managing the problem**

With much of the debate focusing on the social dimensions of the epidemic, there was a feeling - articulated by Kalpana Jain - that the time had come to question the system and the management of the problem.

Kalpana, who has been studying the scenario for a book on the subject, said that the enormity of the situation became obvious to her after she had visited care centers in various parts of the country. Her broad impression was that present policies were not working, and that a lot of money

was being wasted because there were whole pockets of people in rural areas who were affected by the virus. She remarked that the situation was of additional concern because HIV incidence was increasing in areas where the people were not even aware of the realities of the epidemic.

She said that what she had seen had changed her whole attitude to the problem, and her approach to it as a journalist. What makes it particularly difficult, according to her, is that there are two worlds emerging in the HIV/AIDS scenario: One comprises of those who are aware and have learnt to deal with it through counseling, nutrition and drugs; and the other of those who have no access to any of these components, and are perhaps not even aware of the implications of their illness. She felt that this divide places a journalist in a quandary: At one level one has to continue work as a writer developing a story; but given a situation where the story itself becomes insignificant in the light of the human tragedy involved, the journalist's objectivity is lost, and the journalist ends up not asking the questions that need to be asked.

It was also felt that it was important for journalists dealing with the issue to come to terms with their own prejudices, upbringing and sense of morality. Moreover, it was felt that they should refrain from being judgmental: In this sense, part of the blame was assigned to the Media itself, for sensationalizing the issue. This was noted as particularly true in states where there is very little awareness: In Bihar, for instance, participating journalists noted that doctors regularly inform the Media regarding an individual's positive status, resulting in discrimination against the individual and his family. Journalists also wondered why levels of awareness and sensitivity were so low in India, considering that the Government and the media have been dealing with the issue for over 15 years.

The concern that perhaps the HIV virus was not the real cause for immune deficiency was noted by the participants. While recognising that malnutrition and poverty were definitely factors enhancing the epidemic, participants wondered what else it could be, given that the same clinical symptoms and sociological indicators were present in most cases. The consensus was in favour of recognising that the HIV epidemic was posing a tremendous development challenge and there was urgent need for media to become a part of the solution and participate in prevention strategies.

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## **Developing Guidelines and Norms**

### **The issues before us**

Positive groups felt that prevention programs were not working as well as they should because the nation was focusing on an alarmist alerting of the public rather than on creating any genuine awareness. This was, they held, fuelling fears and attaching more stigma to the infection, besides putting people on the defensive. They felt that this was resulting in a reluctance to engage with issues concerning sex and sexuality; and, consequently, a no-it-doesn't-concern-me attitude. In the face of this denial they felt it was rapidly becoming important to talk in terms of general health rather than campaigning exclusively on the basis of HIV/AIDS.

Vis-a-vis stigma, it was pointed out that cancer as a disease creates an immediate compassionate response; but HIV infection invariably results in a negative response, because it is immediately presumed that the person has indulged in illicit sexual activity. As a result, people living with HIV/AIDS find themselves having to combat with both spoken and unspoken prejudices.

### **Change perceptions and behavior**

Positive groups felt that the awareness created about HIV/AIDS over the past fifteen years was largely ineffective, because the general public continues to view the infection as incurable, terminal and the result of one's own follies and mistakes. If this is so, the question is: What does awareness mean? More importantly, what has engendered this confused response, and why are people not able to recognize their own vulnerability or the lack of choices? And why are they not able to recognize – or unwilling to recognize - behavior patterns that could apply to them?

The feedback from grassroot interactions was that people were not seeing HIV/AIDS as their problem. The answer, as some participants suggested, may lie in designing messages that emphasize both, the vulnerabilities as well as the need to modify behavioral change. Those that merely suggest the use of condoms will not suffice; nor for that matter, will the rather simplistic ones that proclaim “lust will kill” or “one partner after marriage prevents AIDS”. Fear and coercion, especially, do not change perceptions or behavior.

### **Empowering the vulnerable**

It was also thought that merely creating awareness would not suffice and that it was also a matter of providing choices and creating an enabling environment. A sex worker knows the dangers of sleeping with a client who refuses to use a condom. But what choice does she have? In Durban, sex workers have formed a sort of network and they don't allow those who do not insist on their clients using condoms. Perhaps, sex workers here should be similarly motivated to take the stance their lives are equally important.

Having said that, the participants also noted that for such initiatives to work, it is equally important to sensitize the police, and disarm the people who hold the power in the sex workers' context - the pimps and the local musclemen - because the women are unable to create an enabling environment on their own. Thailand worked wonders with a ruling that sex workers caught without condoms would be arrested.

But what of the countless women who never leave the villages, and are infected by their husbands? And how does one ensure that people with HIV/AIDS don't infect others? You can't put out messages asking HIV positive individuals to use a condom - the government would be accused of promoting condoms, sex, or worse.

In a study done in Vijayawada 12 –14 year olds said they spent 60% of their money on prostitutes. How, asked participating journalists, do you empower street children against HIV infection? Do you provide them with condoms? More importantly, what is the point of informing people if we cannot empower them? And, last but not least, what should a journalist's perspective on the issue be in the light of these questions?

### **Instill a sense of urgency into the issue**

Awareness, it was repeatedly stressed, was of paramount importance; and IEC (information, education and communication) should be a continuing process as long as the epidemic continues. However, it was also felt that it was time for the media to instill an element of urgency into the issue, and advocate immediate government action to get society out of the vicious circle of underfunding and inequity that leads to HIV vulnerability and the marginalisation of affected individuals.

In twenty years, one of the participants pointed out, this could be Africa; which would be tragic, because Africa became Africa because not enough was known about the epidemic. It was also pointed out that instead of tackling the epidemic on a war footing, we are still debating the pros and cons of creating awareness and the primacy of an effective prevention strategy.

### **Making HIV/AIDS a development issue**

The question of how these concerns could be broadened and linked to other development issues also came up, because this is an issue that goes beyond sex to the larger issues of poverty, gender and social inequity. Moreover, as an epidemic that affects everyone, everywhere, it is important to mainstream HIV/AIDS as an issue, by linking it to other issues like migration, trafficking of women and children, sexual choice and orientation, and adolescence reproductive health. This, it was suggested, would help people to identify with the issue, and increase their sense of immediacy and proximity to HIV/AIDS.

### **Sensitizing Editors**

At another level it was felt that it was important to sensitize editors and persuade them to ensure that something is published every day on the epidemic. But this was opposed by those who felt that a regimented, mechanical approach would not work in the long run. The latter group felt it was more important to sensitize editors on priorities. HIV, they felt, should not be seen only as a health issue, but an issue with many social, economic and health-related ramifications.

### **Evolving a Code of Conduct**

The general consensus was that the emphasis should be on a self-regulatory mechanism through a code of conduct and ethics evolved by the Media itself. It was felt that any code imposed on the media by external forces would be counter-productive.

### **Ensure confidentiality of the affected**

Foremost on the agenda were quandaries surrounding the issues of confidentiality and informed consent. The onus, it was felt, was with the journalist to not reveal the identity of the person being interviewed; and also to assure them that their identities would not be misused. Some of the participants felt that at the end of the day it boiled down to the journalist's own conscience and the way s/he uses the material at his or her command.

Nevertheless, it was noted that guidelines of some kind were necessary; especially for fledgling journalists who are new to the field and perhaps not even aware that they were violating someone's confidentiality or rights as a human being. A forum where journalists could deliberate on such vital issues was also proposed.

### **Checking and re-checking information**

Positive groups complained that facts were often misinterpreted and misrepresented, especially in cases where reporters were forced to interact through translators. They wondered if the drafts of reports could be shown to the interviewees. Journalists felt this was not always possible because they often faced deadlines that left them no time to get back to people. Here again the participants felt that the onus should be on the reporter to reexamine his or her notes, and cross check it with the facts in the final story to ensure that the interviewees' dignity has not been violated. Some participants felt the solution lay in allowing only certain specialists to write on such sensitive issues.

### **Develop a style sheet**

It was agreed by all that a style sheet with guidelines on terminology was essential, though much depended on attitude. It was possible, some felt, to use the correct terminology and still damn someone. The question of who would ensure the guidelines would be followed also came up; and the consensus was that the responsibility should lie with the copy editor, who should check the story as he or she sees fit.

### **Maintain Media ethics**

In the case of television, the consensus was that informed consent was imperative and that the person in charge should insist on it. Many reporters felt, however, that in their haste to get a scoop and be the first to flash a report, this would not always be possible to follow; and suggested some sort of watch-dog policy and/or an agency that would monitor the Media. Aggrieved parties

could then turn to the agency for recourse. In this context it was pointed out that in the case of the print media, it is possible to petition the Press Council for redress. It was also felt that a respected media advocate could be given column space to raise questions concerning media ethics and violations in such cases.

## News Paper clippings



# मीडिया में एड्स की कवरेज में संवेदनशीलता नहीं

## विशेष संवाददाता

नई दिल्ली, 8 जून। मीडिया का एड्स के प्रति रुख गंभीरता का नहीं। यह देखा जा रहा है कि वह इस मामले पर पर्याप्त रूप से न लोगों को सावधान कर पा रहा है, न सरकार को और न ही अपने आपको। नतीजा यह कि 1986 में पहला एच.आई.वी. संक्रमित व्यक्ति होने के 14 साल को अवधि में ही देश में आज 38 लाख से ऊपर संक्रमित व्यक्ति हो गये हैं। यह भी पाया गया है कि मीडिया को कुछ भी एड्स के बारे में प्रस्तुत करना है, इसमें मानवीय पहलू गायब होता है, खासतौर से भयानगी चर्चों में इस मामले पर पर्याप्त गंभीरता नहीं बनायी जा रही।

'बीटर बिटे एडवोकेसी एंड रिसर्च' को और से आज यहां एच.आई.वी. / एड्स का जनसंख्या माध्यम के लिए आयोजित राष्ट्रीय परिषदों में मीडिया को भूमिका पर काफी रोचक चर्चा हुई। एक पत्रकार ने कहा कि बिटे अल्प सत्ता-प्रतिष्ठान के खिलाफ ज्यादा प्रचलित करते हैं जो आपकी भीरे बिटे दक्षिण दिशा जाने लगता है। एक गण यह प्रकट की गई कि भारतीय मीडिया अनेक बार परिषदों मीडिया का अनुसंधान करने लगता है। यह भी कहा

गया कि संक्रमित लोगों के आंकड़ों के बारे में पत्रकारों के मामले जनसंख्या का पर्याप्त जर्जिया नहीं। जो भी आंकड़े सरकार दे देती है, उसी को प्रसारित किया जाता है। गिनती क्षेत्र से कोई आंकड़े मिला नहीं रहे। कारण यह कि सरकारी आंकड़े अभी पर्यंत गलत हो सकते हैं।

एड्स के बारे में एंटी रेट्रोवायरल दवाओं की कम हो गई बीमता को चर्चा होती है लेकिन इस बारे में जानकारी नहीं दी जाती कि केवल दवा का ही खर्च नहीं होता बल्कि इन महीने तमाम तरह के ज्वोगाहता परीक्षणों का भी खर्च आता है। इन दुर्घटना पर एड्स का सारा प्रतिष्ठान कोई चर्चा नहीं करता और इसलिए लोगों के मामले सन्वाई नहीं आ पाते।

कुछ अन्य पत्रकारों ने कहा कि एड्स महत्व स्वरूप का मुद्दा नहीं बल्कि इससे जुड़े सामाजिक तथा मानवीय पक्ष भी हैं लेकिन उन और ध्यान नहीं दिया जा रहा। मीडिया में एड्स की रिपोर्टिंग पूरी तरह इस तरह चल रही है मानो यह केवल मेसम से जुड़ी बीमारी है जबकि इससे जुड़े अनेक विकास संबंधी पहलू भी हैं। नतीजा यह कि आज लोगों को एच.आई.वी. अदि के बारे में जानकारी कम, अधूरी और विकृत रहती है।

9 Jun 01  
Dainik Hindustan  
New Delhi  
**NO SENSITIVITY TOWARDS AIDS COVERAGE IN MEDIA**  
Special Correspondent  
New Delhi, 8 June.

Media is not serious about AIDS coverage. It has been observed that the media is not able to sensitize people, governments or itself towards the seriousness of AIDS. The results are that for the fourteen years from the first spotting of the infected person in 1986, the situation in the country is that there are more than 38 lakh infected persons. It has also been found that whatever the media is providing about AIDS, the human aspect is absent, especially in the regional newspapers this aspect has not been given any seriousness.

There was interesting debate today at the national dialogue on role of mass communication in FHV/AIDS organised by "Centre for Advocacy and Research". One of the reporters informed that the media is sidelined if they deeply investigate about the organisation. One view was also put forward that the Indian media is following the western-media. It has also been said that for investigating figures for the number of infected persons there are no proper channels. Whatever figures the government provide, that is only distributed among, the media. No figures are available from independent organisations. The outcome is that the government figures are incomplete and wrong.

There is discussion on reduction of AIDS antiretroviral drugs but there is no information provided on the other expenses incurred on laboratory analysis apart from the medicines every month. The AIDS main organisation does not want to divulge on these issues and therefore the truth is not exposed.

Some other reporters said that AIDS is not just issue for health, but also the societal and human aspects are there, which are totally ignored. AIDS reporting in the media is just limited to only sex related disease whereas there are many more development related aspects also. As a result, people have less, incomplete and distorted information related to HIV.

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## Annexures

### Linkages and limited choice

Ms Beverly Brar

Program Advisor – UNDP HIV and Development Project, South and Southwest Asia

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From past experience in working on the ground and at the policy or operational level of the epidemic for a decade or more, it has become clear that there are strong linkages between the spread of the virus and the vulnerability in people's lives. We know that HIV/AIDS is preventable; that those who have information and choices can protect themselves from exposure to the virus. So it follows on that the most vulnerable are those with limited choices.

We have also learnt that just giving information about HIV/AIDS will not suffice when people are struggling on a daily basis to survive especially young men who are away from home and their regular sexual partners for extended periods of time. As one sex worker remarked while speaking of males. "This male himself maybe a poor, displaced man". Is he then in a position to value his own life or motivated enough to take steps to protect himself"?

And as for women, we know that they are more vulnerable for biological reasons and that when they don't have control over their sexual circumstances, they cannot control the HIV virus and find themselves in non-reversible situations. Often this takes place in their own homes. At a recent meeting with People living with HIV/AIDS four of the six women present had been infected by their own husbands who were aware that they were HIV positive. But the most vulnerable are women and girls who have been trafficked into sex work or any other form of forced labor. They are subjected to sexual exploitation and abuse which is totally beyond their control. Even if they manage to get out these situations, they are rejected by society particularly if they have HIV/AIDS.

A climate of stigma and discrimination against people living with the virus cannot serve to fulfil their needs. We also know that for programs to work and be effective active support is required from those who have experienced the disease. The highest priority, of those working on this issue should be to try and generate conditions in which people are empowered to protect themselves from infection and live with dignity in society.

### The problem before us

Swarup Sarkar

Head of the UNAIDS Inter-country team for south-Asia

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When the first CDC report was published twenty years ago on June 5<sup>th</sup> not many realized that this was going to be the biggest killer in this century. More than all the numbers killed in the wars put together. But even today, we are ourselves not aware, perhaps we are not convinced that it is going to be the biggest killer of the adult population in India over the next ten years. So there is need to educate ourselves and convince ourselves that we have a problem. Today, there is a prevalence rate of more than 2 percent in the general population, which is a rate that is only seen in five or six countries outside Africa. There are also five hot spots where it is more than 2 percent a fact that is not being highlighted because our notion of HIV is that it is a problem of Africa where people are very promiscuous but we are different.

The other important point is that in 1986 we did not know how prevention worked. We tracked the epidemic and said it was predictable but not that it was preventable. It also took us five years to come up with a project or model that works. To realize that the sex workers need space and that it is the client who decides condom use. What we also do not know is how to evolve a prevention program that succeeds. So the epidemic is progressing and the rate of progression is very high but we are not doing enough even though we know that the disease is preventable, the epidemic is preventable.

One reason is the level of political commitment. The Prime Minister, in his Independence Day address to the nation had equated HIV/AIDS as one of the three main issues facing the country. Yet, when leaders from all over the world were meeting for a special session of the UN on HIV/AIDS no politician from South Asia was present because HIV/AIDS is considered to be a disease of Africa. This is unfortunate because if a difference could be made it is in Asia. In Africa huge sums of money have to be spent to mitigate the impact of the epidemic and on care. Here money would be spent largely on prevention. But this is a point that is not understood by Asian leaders and politicians.

Then again there is the issue of resources. Thailand, which has had success in dealing with the epidemic, spends \$1.3 per capita. In India that would amount to \$ 1 billion but we spend \$60 million which works out to 6 cents per capita. There is need for huge investments today because if we don't spend today we will have to spend a great deal more later on treatment and care of positive people. Unfortunately, donors are not aware of how much money is required. And often the money they give is not utilized. So we are caught up in a vicious cycle of under funding by the donor and under spending by the government and even NGOs. Moreover, there is very little debate on the need for resources and resource utilization.

What is more even after 6 to 7 years of HIV programming coverage of vulnerable populations remains very poor. Even in very good states only about 40% of such vulnerable groups as sex workers are reached. Nor for that matter do our programs touch the migrant population or the 250 million young people who we know are going to be in the fourth wave of the epidemic. If their future is secure, everyone's future is secure. But the question is who is going to do it. We have not addressed this problem either within our programs or outside of them and neither is there an enabling and supportive environment. The burden of HIV prevention is with small NGOs and sex workers who are supposed to do peer- education. There is no large-scale awareness of the issue in society nor an open environment as in Thailand where messages which come directly from the PMs office. Open, explicit messages asking young people to use condoms if they are visiting commercial sex workers.

And there is also the problem of stigma. If only we could remove the stigma attached to the disease and everybody could talk about it the whole scenario would change. One would not have to hide one's status from others and everybody would be protected and society would take care of them.

## **Media Mapping**

Akhila Sivdas,  
CFAR

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The Centre for Advocacy and Research has conducted the media assessments at two levels. At one level, the Indian Network of People Living with HIV/AIDS was asked to respond to a set of press clippings from the point of view of people affected by HIV. It is important to keep in mind the fact that while a lot is being done it still falls short of their expectations, their concerns and their needs. Their response, however, is an indication, of the ideal level of sensitivity that the media

must aspire to. At the same time their findings have thrown up a number of ethical issues and while all of us might not be guilty there is no denying the fact that there is a tendency in the profession to commit such travesties.

The other, was our own monitoring and analysis of content. One thing we found was that there is a lot of coverage of the issue and that nobody was ignoring the issue or neglecting it and that everyone was doing their bit to raise awareness. In fact, the coverage is significant in the English Press and is steadily growing in the Language Press, especially the Hindi Press. We also found that there was a lot of interest, for whatever reason in the human-interest aspect of the issue especially the stigma and discrimination that surrounds the disease in rural areas. Journalists are so shocked by what they see and hear that they write extremely strong, moving and compelling copy when they return. There is also a lot of focus on women, prisoners, children and other vulnerable groups so it is not as though journalists are not affected by the issue.

In view of the tremendous coverage the issue received we picked on two samples. One was to look at the suspicion that on World AIDS Day or on a campaign day there is a spurt of coverage. Also, if this was token coverage or does it have something to do with the compulsion of the day? We found that such commemorative days did indeed give scope for very concentrated coverage and that while many of them were press releases on the events of the day about 25 to 50 percent of the coverage comprised of in-depth articles that examined various aspects of the concern. These included human rights issues, the impact on men, women, young people, access to treatment and care etc.

A random analysis of a month without an event was also done. We took March 2001 and found fairly extensive coverage because there were numerous time pegs. NACO had just put out its surveillance data and there were several awareness drives perhaps because the fiscal year ends on March 31 and funds have to be utilized. There was also several reports on actual government allocations for HIV/AIDS and the reactions of state governments and state AIDS Control Societies to the allocations.

So quantitatively, the Media is neither ignoring the issue nor marginalizing it. A qualitative assessment meanwhile revealed that Media played a significant role in influencing the developments vis-à-vis two issues: the CIPLA drug controversy and the policy decision on mother to child transmission. Taking on a pro-active role, they have informed people about the trials, drug regimens etc. All this went a long way in helping the government to take the decision to provide free treatment across the country to stem this vertical transmission. Similarly, on the CIPLA issue, there were numerous well-researched stories on the entire controversy. They gave a larger image to the entire HIV issue and also informed people of patent laws, the WTO, the TRIPPS Agreement etc resulting in an opening up of this issue. What was also noticed was that though this is a complex and complicated issue the Media did not compromise on the quality of

## Media mapping

### TABLE ON ISSUES COVERED — MARCH 2001

Issue	No. of Reports
Surveillance Data 2000 - Status of HIV/AIDS	17
Awareness Programmes	26
Treatment and Care - Discrimination, Negligence etc.	24
Financial Resources for HIV/AIDS	12
AIDS Vaccine	8

Drugs (Cipla)	7
Human Related Stories	5
Report on Tribal Women	5
HIV and Women	4
HIV Detection Kit	4
Award for AIDS Research	4
HIV & Children	3
12 <sup>th</sup> International Conference on "The Reduction of Drug Related Harm"	2
HIV/AIDS in South Asia	2
Legal issues related to blood safety	2
AIDS and North East	2

coverage and the information that was put out. In fact, it warned that this was but the beginning of a very long battle and that by no means are all Indians going to have access to them because at \$350 as being cited by CIPLA it is by no means accessible or affordable.

So our concerns about coverage are not with regard to quality because the Media today plays a critical role and people are not just honing into the Media, they are also finding out and clarifying whatever concerns them. But what the Media is doing is instilling a sense of immediacy, and a sense of commitment and responsibility that was not there before.

However, what is of concern is the need to reshape coverage, especially the manner in which the print Media is organized. Conventional newsgathering processes somehow inhibit the kind of journalism and the kind of investigations that issues like this demands. Editors must invest in creating some amount of highly specialized reporting with well informed and well investigated reports that will look at this issue not just as a development issue but in the context of the whole situation. Reports that will take people into confidence and treat Media as part of the problem and part of the solution and enable it to engage in what is called civic journalism. This is absolutely imperative on an issue like this.

There is also a lot of star-struck writing in journalism that is nudging out developmental and other serious writing. And this is not just in term of column space but of how well a report is done. Because it has been noticed that if a report is done well people will remember and recall it. So the intensity of the work is important. Coverage also needs to be reshaped so as to give a role to civic journalism. Also, of concern is the manner in which very desperate voices, unrelated experiences and unrelated testimonies are strung together to make a report newsworthy. So reports are often just strung together and instead of informing you they become news reports with a lot of issues strung together and are none the better for it. Media, also has a tendency to become self opinionated, to put itself in the context and knit together disparate things. To give itself an arbitrating or mediating role. But what it is doing in actuality is playing a highly misinforming role in this process of arbitrary juxtapositioning of information.

**Media mapping**  
**TABLE ON ISSUES COVERED — MARCH 2001**

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## **Lack of trust**

Lila Banta Singh  
President of the Manipur Network for  
People Living with HIV/AIDS

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Media has played a vital role in advocating for the rights of people living with HIV/AIDS to a certain extent. However, most of the reports seem to be exaggerated even when they are dealing with discrimination and the rights of people living with HIV/AIDS. What I cannot understand is how a normal society is different from a society where people are living with HIV/AIDS. Reports are sensationalised to make an impact. Reports of HIV positive people committing suicide affects people living with HIV/AIDS. As for rights, I don't know whether most reporters know about the rights of patients, the issue of confidentiality between patient and doctor, and of people living with HIV/AIDS.

Reporters need to do some more research before filing the report. For instance, a leading national daily carried a story about a woman in Burdwan, West Bengal, who got the virus from her son's blood through transfusion. The hospital had passed the blood as HIV negative. The son died nine days after he was declared positive. The doctors subsequently said that it takes between six to 36 weeks for HIV to become full-grown AIDS. All this is very confusing because if there is full-grown AIDS what is half-grown AIDS? What kind of a statement is this coming from a doctor who is responsible for treating people living with HIV/AIDS?

I have experienced that trust is missing in the relationship between the media and PLWAs. When one of my friends was bedridden, a photographer wanted to take his picture. My friend refused but after much discussion, the photographer promised something and my friend agreed for the photograph. The photographer never returned and my friend died a long time back. These kinds of incident make us feel that we cannot talk or open up with the media. There was also the time when a leading magazine wrote a story on the Manipur Network for Positive People. They used pseudonyms but did not give a clarification that the names had been changed for reasons of confidentiality, It led to a lot of confusion and misunderstandings among us. Moreover, the media never sends us a copy of the article or interview and does not even tell us when it will appear. These kinds of things are very disturbing.

Instances of insensitive reporting are disturbing. Use of pseudonyms without a clarification that names were changed for the sake of confidentiality makes people living with the problem feel they cannot open up to the Press. We need to have more workshops like this at the state and national level to understand and develop a strategy for more precise reporting. Reports should be written on discrimination and in conclusion they must say that if such discrimination is happening, here is where you can report it. That would be very helpful.

## **Dangerous trends**

Nirmala Lakshman  
Joint Editor, The Hindu

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One of the basic issues journalists have to contend with is the kind of slotting that prevails within newspapers. So if some of them develop an interest in a subject, say the medical beat or development, it is of their own volition. The space given to issues like development is also generally in the main section in the form of news items with very little space or scope for long discussions on these issues. Sometimes they are relegated to the supplements but the supplements have their own priorities, namely glamour, entertainment and gossip. So it is difficult to create a balance between serious issues that need to concern us and the kind of information a lot of readers want.

A random assessment of the kind of coverage given by the Hindu to HIV/AIDS since January of this year revealed that there were about 40 items of which 12-15 concerned the pharmaceutical aspect of the issue. Most of the others were spot news, small news items and press releases from drug companies like CIPLA. There were also a few reports on vaccine trials and new drugs and experiments being carried out in western countries and only two small reports on the social and human dimensions of HIV/AIDS. And they were not comprehensive by any means. There was a lot of discussion on WTO and the drug issue where I feel the Media played a very pro-active role.

An AIDS activist working in Tamilnadu also felt that the Media had come a long way vis-a-vis HIV/AIDS, especially in terms of frequency but they, especially the English language Press, tend to be event oriented rather than issue oriented. I can also add that some of the best discussions on this subject in the Hindu have come from the initiative and involvement of committed individuals.

Frontline, our sister organization, had done a lot of supplements and special reports dealing with HIV/AIDS and again unfortunately, all these things tend to be pegged or targeted towards events such as World AIDS Day or the twentieth anniversary of the epidemic. What happens when this is done is that the interest of the reader is not sustained. Moreover, it gives little scope for some of the issues that have been raised today like its link to poverty, funding or gender concerns simply because there is no consistency in the coverage.

An activist I spoke to felt that in the vernacular newspapers, in Tamil for instance, there seemed to be an element of schizophrenia. Sometimes it viewed the epidemic very unsympathetically through the lens of middle class morality with very sensationalized presentations or stories of people who are living with the problem. But on rare occasions there have been a series of discussions by doctors who are working with HIV/AIDS. But, again, she felt that it was largely inadequate.

Another group of positive women I met also agreed that the awareness level had increased. But they had some reservations because the articles, especially in the language newspapers tend to focus on despair and create dread and fear among the reading public. Moreover, there were highly misleading vis-a-vis the outcome of the disease. Ashok Pillai of INP+ has told us of the kind of prognosis that is often handed out to patients and families resulting in a sense of terrible despair.

It has also been noticed that there is very little information on drugs and the treatment that is available. Of course, costs are prohibitive but we know that a huge amount of funding comes from the west. UNAIDS, various governments and NGOs also have a lot of funds for work in this area but the public is not aware of it and neither do those living with the problem. So they don't feel they have any access to this kind of support.

There is also this feeling that treating HIV as a special illness only reinforcing the stigma attached to it. And this feeling is further reinforced by the sort of visuals, slogans and posters that are seen on walls and auto-rickshaws. Like the ones saying "lust kills" or "be faithful to your wife"

with a skull and cross bones drawn across it. None of this takes us beyond talk of safe sex to the kind of behavioral changes that many of us have been speaking of this morning.

Another dangerous trend that HIV activists have noted is that some Tamil television stations are carrying advertisements of alternate cures like siddha which promise cure within a few days or months. But when such cures fail to work and people go back to the television station, the station absolves itself of all responsibility by saying that it was a paid advertisement and they know nothing about it. This then takes us back to the issue of guidelines and what we as editors and people who are involved with decision making across different kinds of Media should do in such situations. Do we have some kind of regulation? And if yes what should that be?

## **The human dimension**

Chandan Mitra  
Editor, The Pioneer

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I think a major part of the problem is that there is inadequate realization of the seriousness of the issue and the degree of realization that very often happens in the reportage of HIV/AIDS results in symbols and stereotypes. Very little effort is made to get to the bottom of the problem and to discuss issues in depth. Of course there have been very, very honorable exceptions. But it is a fact that Media has not fully alerted itself to the issue and the responses and reflexes of Editors have not been suitably conditioned. More efforts must be made to involve people in decision-making authorities across the Media and sensitize them to this preponderance. This is important because the domination of market forces in determining what is news, what people like to read and what they want to watch very often obscures the need for presenting issues like HIV/AIDS with the seriousness and length it requires and deserves.

One point I would like to make is that very often in this kind of reportage the human element is missing. We tend to see issues of this nature as part of a larger problem resulting in a lot of misinformation, juxtapositioning of one thing over another and an end product that is confused and unfocussed. I think both in terms of reader interest and creating awareness it is extremely important to keep the human dimension in mind and to focus on individual cases and through the eyes of people who are living with the problem. Television is very event-oriented so issues like this get pushed out of news bulletins and even other programs but it would be an excellent medium for this. And if the human dimension is kept in mind I think it will have a tremendous impact on the viewer and also go a long way in sensitizing people within the Media. All this is not to say that this has not been done but I think this sort of focus on individuals would be extremely effective and should be done more regularly by all sections of the Media.

There has also been some discussion on the social dimensions of the issue, which is yet another area where there is inadequate knowledge and understanding. I know it is a very large issue but one should not obfuscate it by talking in terms of poverty, malnutrition, and ignorance and therefore AIDS. If you do that the obvious kind of response from readers is that these are such large issues which cannot be resolved in the foreseeable future. So can you really handle this? In other words, a certain kind of despondency and cynicism sets in if we talk only of larger issues without focusing on the specific problem. But what nevertheless needs to be hammered home is that there are sections and segments of society which tend to get more affected due to the lack of options available to them and what are the kind of policies we should have so as to at least enable them to get information. There is so much misinformation doing the rounds that if a person really wants to know, to ask basic question they have no place to go to. Nirmala Lakshman mentioned the sort of violent and hilarious posters that are put up which only intimidate

people. So it is important to provide people with information on where they can get authentic, first hand information on this subject. This is another area where we could put our heads together and do something concrete. Perhaps, newspapers could regularly devote space to this issue through their columns.

It is also important to sensitize the Indian language publications on this subject. My general perception is that they are not taking it seriously because you do not find a reflection of this concern in their articles or health pages. So if we are talking about the larger problem of poverty, ignorance, and malnutrition and people from less privileged sections being in greater danger there is an obvious linkage to language access. So, it is very important that the language publications and channels are involved in this exercise. Those in a position to influence government policies need to convey this to policy makers.

## **Acquired Death: the North-east Scenario**

D.N. Bezboruah  
Editor, The Sentinel

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It is not often that one goes out of one's way to acquire an incurable disease and to court inevitable death as a consequence. Barring the tragic cases where Acquired Immuno-deficiency Syndrome (AIDS) is passed on to one's spouse or sexual partner because he/she is unaware of the other having acquired it, or where the disease is transmitted by a pregnant mother to her child or when it is unknowingly contracted in the course of blood transfusions irresponsibly administered, the majority of the cases of full blown AIDS evoke little public sympathy for the simple reason that people seem to morally judge the character of those affected through multiple sexual partners, addiction to drugs taken intravenously or through sheer ignorance. And the rate at which this disease is spreading all over the world and especially in sub-Saharan Africa is enough to send a chill down one's spine.

According to the data available till December 2000, the total number of people in the world living with HIV/AIDS till then is 36.1 million, which includes 16.4 million women and 1.4 million children below the age of 15 years. People infected with HIV in the year 2000 alone are 5.3 million, of which 2.2 million are women and 6000,000 children below the age of 15. What is even more shocking is that 23.44 million of the 36.1 million living with HIV/AIDS are inhabitants of sub-Saharan Africa, where 8.8 percent of the total adult population is infected. However, this bit of statistics fails to reflect the alarming picture in some of the sub-Saharan countries like Botswana, Swaziland, Zimbabwe, Lesotho, Zambia, South Africa and Malawi where 35.8, 25.25, 25.06, 23.57, 19.95, 19.94 and 15.96 per cent respectively of the total population are living with HIV/AIDS. What is even more saddening is that in the case of the sub-Saharan countries, without a single exception, the number of infected women between the ages of 15 and 49 is greater than the number of men of the same age group. It is hardly surprising that in sub-Saharan Africa, the number of children with HIV/AIDS should be abnormally high too.

As far as India is concerned, the data available till October 31, 2000 would indicate that there are 15, 606 cases of full-blown HIV/AIDS reported to the National Aids Control Organisation (NACO), of which the highest number (7,787) are in Tamil Nadu. The other States where the number of HIV/AIDS cases is alarmingly high are Maharashtra(3657), Manipur (706), Karnataka (671), Madhya Pradesh(605) and Nagaland(71). Though there are States like Guujarat (360), Uttar Pradesh (259) and Delhi (268) in between, the spread of HIV/AIDS in Nagaland is a matter

of greater concern because of the percentage of infected persons rather than the total figure. Thus, Tamil Nadu, Maharashtra, Manipur, Karnataka, Madhya Pradesh and Nagaland were considered the worst States of the country in terms of full-blown AIDS situation. On May 23, Prime Minister Atal Behari Vajpayee called upon the chief ministers of the six most AIDS-affected States of Maharashtra, Andhra Pradesh, Karnataka, Tamil Nadu, Manipur and Nagaland to intensify prevention activities and focus on awareness of young people who are the most vulnerable. "These should include programmes for schoolchildren, street children and other young people to help them adopt a responsible lifestyles. Besides, we can also actively involve the religious establishments who can have a strong positive influence over large sections of our society," he said. Union Minister for Health and Family Welfare Dr. C.P.Thakur also said in Patna last month that India has 3.8 million HIV cases and ranks next to South Africa in terms of estimated cases. However, these are the NACO figures for the year 2000. If one takes into account the rate of annual increase in the number of HIV/AIDS cases in the country, this figure could well have exceeded four million even as we are talking about the problem now.

In the Northeast, the HIV/AIDS situation is even more alarming because there is a very potent source of infection not shared to the same extent by the other State of the country, viz a viz drug abuse. Both Majipur and Nagaland share a border with Myanmar (Burma). And the Golden Triangle is located where the borders of Myanmar, Thailand and Laos meet as the map shows. It is also a well-known fact that the production and sale of narcotic drugs (mainly heroin) is controlled by militant groups like the Kachin Independent Army (KIA) of Myanmar that has imparted training in guerrilla warfare to several militant groups from Nagaland, Manipur and Assam. One of the stipulated preconditions of training for militant outfits is that their cadres would have to function as couriers for narcotic drugs from the Golden Triangle. And since the international border between Myanmar and Manipur is virtually an open one, a large part of the drugs traffic is through Moredh, a border town in Manipur. There was a marked increase in the production of heroin in the Golden Triangle following the crackdown on the Mexican centers in the late seventies. Not surprisingly, by 1986, the Golden Triangle accounted for about 20% of the US drug market. What was going out through Moredh and other entry points in Manipur was pure heroin- each kilo of it extracted from 10 kilos of opium. The sizeable narcotics trade though Manipur has resulted in more young men of Manipur becoming drug addicts. The intravenous intake of heroin and the sharing of needles by drug addicts is a major concern especially in view of the vulnerability such behaviour causes for HIV/AIDS infection in both Manipur and in neighboring Nagaland.

In the initial stages, when there was suspicion about the possibility of large-scale drug addiction in Manipur giving rise to HIV/AIDS infections, an HIV sero-surveillance programme was taken up by the Regional Medical College (RMC) of Imphal almost simultaneously with other part of the country. But none of the 2,322 sera samples screened by ELISA up to September 1989 was found to be positive. However, in October 1989, HIV antibody was detected in a 39 year-old businessman involved in smuggling as well as intravenous drug use. Since then and uptill the end of June 1990, 1,564 serum samples were collected from intravenous drug users (IVDUs) for HIV antibody testing. The samples were screened by ELISA, using Wellcozyme HIV recombinant kits at the Regional Medical College, Imphal and were confirmed by ELISA and Western Blot (WB) tests (Du pont kits) at the National Institute of Cholera and Enteric Diseases (NICED), Kolkata. The results of the HIV antibody tests are given in Table1. It will be seen that 853 (54.5%) of the 1,564 IVDUs were found positive for HIV antibodies since the first sero-positive case among IVDUs has been detected in October 1989. The majority of them were male (97%) while only three percent were female. As for the age break-up of the sero-positive, over 85% of the IVDUs are below the age of 30 years, with the 20-24 age group alone accounting for 42.9% of the cases which those in the 26-30 age group constitute 30.2%. The most shocking revelation was that 12.6% of the sero-positive IVDUs are in the 15-19 age group.

The cost of heroin in Manipur is around Rs. 400 to Rs. 500 per gram, though it is also available in packets of different sizes costing between Rs.20 and Rs.50 per dose. Any kind of available water is used as the solvent, and the drug is dissolved in any shallow container. The solution is then taken from any improvised syringe (generally an ink dropper) which is connected to the hypodermic needle shared by several users. The needles too are just cleaned in plain water. The scenario is much the same in Nagaland.

I had started out by expressing concern about Nagaland even though the number of HIV/AIDS cases in the State may not be very high in terms of raw figures. But considering that the population of Nagaland has gone up to just under 2,000,000 from the 1991 census figure of 1,200,000, the percentage of HIV/AIDS infected persons has increased alarmingly in the State. Of 9,192 persons screened up to June 30, 2000, as many as 477 were found to be sero-positive, giving Nagaland a sero-positivity rate of 51.69 per thousand - second only to the abnormally high rate of 165.55 per thousand in Manipur. Well behind Nagaland is Sikkim with 18.84 per thousand and Assam with 15.09 per thousand.

The tragedy of Manipur is that while in the beginning only three percent of the HIV/AIDS-affected people were women, this percentage is gradually increasing with the HIV - positive men passing on the infection to their unsuspecting wives, who in turn pass it on to the new-born progeny. And in Manipur, the percentage of women who have acquired AIDS from their husbands has continued to rise at an alarming rate.

Another major source of AIDS in the Northeast has been unearthed by a recent study of how migrant labour are becoming more and more vulnerable to HIV. The study conducted in Lad-Rymbai of Meghalaya reveals how the migrant labour working in at the coal belt to Meghalaya and living in slums have proved to be highly vulnerable. Among them are a large number of Bangladeshi labourers and truck drivers from the heartland States of India. And all over the North-east, HIV-positive persons are also acquiring tuberculosis.

Regrettably, neither the surveillance system nor the testing and counselling facilities in the northeastern States is adequate. Nor do the STD clinics have counsellors. This is most unfortunate, considering that the chances of those with STD becoming HIV -positive are about 10 times higher. Since the possibility of undoing what AIDS has already done can be ruled out, it is imperative to keep down the number of people who are likely to acquire the disease in the future. One way out, of course, is through sex education in schools. All prudes who stand in the way of sex education ought to realize that the choice is between prudery and death through ignorance for a large number of young people. It is, therefore, heartening to learn from the Union Minister for Health and Family Welfare (through his recent statement to reporters in Geneva) that the Government proposes to introduce a national-level educational program in schools on sex education in an attempt to combat the frowning menace of AIDS. This would be in addition to the Mother to Child Transmission Program (MCTP) announced earlier. However, the Government must find ways of ensuring that whatever little of the meager allocation for health-care is available for the prevention of AIDS is judiciously used and scrupulously monitored. The emphasis should be on voluntary counseling and testing, especially in the antenatal clinics. This will provide the much-needed awareness to mothers and wives. Finally, there is a lamentable lack of scientific de-addiction programmes in the country, specially in the light of relapse to drug abuse in 93% of the cases. Since not all IVDUs have contracted AIDS, there is some possibility of prevention with

proper counseling through scientific de-addiction programs. The major thrust has to be aimed at that segment of the population who end up at deaths door through ignorance.

And this is where the media can play a major role in creating awareness not only among counsellors and educators, but among the general public - specially on the need to introduce the right kind of sex education at the right time. There are two other goals that the media must pursue far more assiduously. One is to counter the common perception that we need not worry too much about those who have already acquired the disease, and that it is far more pragmatic to concentrate on awareness programmes and on saving the coming generations. We tend to forget that we need to involve people living with HIV in the response. There is also the need to address the problem created by the kind of ignorance among the people that leads not only to people with AIDS being ostracized and denied admission to hospitals but even those suspected of being infected having a tough time getting any kind of medical help given the attitude of most doctors, nurses and hospital administrations towards HIV positive people.

**Table 1: Distribution of confirmed HIV seropositive persons according to risk groups and sex in Manipur**

Risk group	Male	Female	Total
IVDUs	827	26	853
Blood donors	22	0	22
STD and other High-risk groups	20	4	24
Total	869	30	899

**Notes:**

1. 911 samples were ELISA positive out of the 935 positive samples received from RMC, Imphal.
2. Out of the 911 positive samples, 899 were confirmed as positive by Western Blot, 4 were negative and the rest (8) were indeterminate.

**Table 2: Results of screening for HIV anti-body with the serum samples from Nagaland**

Category	Sample	Positive	
		ELISA	Western Blot
Drug addicts	22	11	11(50%)
Others	58	2	1 (1.7%)
Ttotal	80	13*	12 (15%)

- One ELISA positive gave indeterminate result by W.B.

## Things we need to do

Ms. Sathya Saran,  
Editor, Femina

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I'd like to just share a few thoughts. One is that my magazine Femina has a page on HIV/AIDS that appears regularly every month. It started off as a sponsored page with Lara Dutta answering questions from readers. I put Lara Dutta there because she is working for HIV/AIDS as a Ms. Universe and it's easier for a reader to talk to a celebrity. They find it much easier to communicate, they want to communicate and they are happy to know that she is responding to their questions. It started off as a sponsored page and though the sponsorship has suddenly run dry I'm continuing the page because that is my personal commitment to my readers. Just because the money doesn't come for the page doesn't mean that the problem has gone away. I'm hoping that nobody who matters realizes that this page is not making money because why should the magazine deal with such a subject but that it is my personal commitment.

As someone who wants to take this battle against AIDS to the reading public in order to motivate them and create awareness and concern, I have found that we have to cope with all sorts of mental blocks. When we spoke to teenagers while doing a cover story on HIV/AIDS we found a rather "devil may care" attitude. I think this attitude is typical of the young today in the context of colleges like Xavier's, Sapphire's, SMTT or Mitibai. The attitude was 'Oh! C'mon. Don't bore us". Or " Don't tell us about it, it doesn't happen."

And when it comes to NGOs there is another problem. I'm constantly talking to NGOs on everything from teenage sexuality to environment, I mean all kinds of NGOs and saying use my magazine, this is a powerful medium. But I am not mainstream journalism, so I don't count. I was surprised when I was invited today because I'm never invited. As a magazine we are not invited because we are a woman's magazine, for heaven's sake, who wants a woman's magazine? And then we are glamour magazine. We have Ms. India's and Ms. Universe's which is again...ok that's the packaging. But any NGO who bothers to look at this magazine will know that there is a lot on environment and health. There is always a lot on health and a lot of our cover stories, at least twelve out of fifty two are health related. But unfortunately, NGOs don't communicate.

When we did a whole nation wide survey on teenage sexuality. I got people to get me facts. We compiled it and published a cover story. Three days later I was asked to inaugurate a seminar of the Family Planning Association of India and I ironically released their booklet on teenage sexuality. If they had only given it to me, I would have given them such a wide forum to publish and publicize their findings. We would have also been saved a lot of work that non-professional researchers were forced to do!

So this is a problem. NGOs must realize that if there is work going on about HIV/AIDS, and whenever there are little successes, they should be written about. But we don't want sob-stories. We want successes because we want to motivate people to follow those successes and yes, if there is a sob story that turns into a success, we want that. But we don't want to say that we are a nation dying of AIDS and not say how not to die of AIDS.

Another observation I need to share is that the Government does not even believe we exist. I mean "Femina! What is that?" is probably what they feel. I don't get any handouts I mean mainstream newspapers obviously get handouts. At the Times of India, they are getting handouts about AIDS, big, small, medium-sized, I haven't seen one government DAVP, whatever, nothing. At least they can alert us to a story idea.

I have fortunately or unfortunately been in Africa, and seen those hospitals where people are waiting to die supposedly of tuberculosis but actually of HIV/AIDS and other infections including

tuberculosis. There is no money for treatment. They know there's no money for treatment. All they have is dedicated nurses who cry through the nights because they know the patient is going to die and they are doing their best to make him die in peace. I can see it happening here. I think Kalpana Jain has already seen it happening in India. I can see that happening to our people and I don't know what to do about it. Hopefully something will come out of our deliberations today.

I have, in our magazine, developed some guidelines for journalists which I would like to share with you and which you can also add to. The first is that when we talk about HIV/AIDS, of people living with, people who are suffering because of it and families who are affected by, we talk with empathy. We talk as if they are one of us, we talk as if it could have happened in our family. The person could be a sister, she could be a cousin, she could be a neighbor, she could be a friend, because we deal mainly with women, I'm using the term 'she' but it applies as much if we talk to a man. Empathy is important because empathy lights another lamp of empathy and another. That would be one way of changing public opinion and saying "don't look at them with hatred, look at them with love". Maybe they will then look at them with love or maybe they will look at someone they know who is suffering with the same set of eyes that you used. So empathy is important. Putting yourself in their place is important because that cuts the divide between you and them. The question of you and them should not be there. It's after all the same kind of person.

Confidentiality, everyone knows, is important. I think it is as important as when we talk or write about a rape-victim. Earlier, we used to say so and so was raped rather than so and so raped or so and so is accused of rape. So I think that is important because the stigma still exists. So somewhere we have to ensure confidentiality whether its in the press, whether its in television. Wherever it is I think we should respect their way of life as was pointed out earlier and I also totally agree that judgmental attitudes don't help. When this magazine used to be judgmental our circulation fell to 63000. Then we did a survey and the overwhelming response was- you preach we don't want preaching. If we want to listen to preaching, we'd go and listen to our mothers.

So the moment you turn judgmental, shutters are pulled down, eyes are closed, ears are shut and everything becomes closed. What needs to be understood is this is their way of life, their circumstance. If we were in that circumstance, we may not be any different. Respect their way of life, respect the circumstance, respect the situation and respect what has happened because of the situation and then take it from there.

And of course support, support by going beyond journalism. Sometimes all they want is someone to listen to them. Sometimes, all a widow wants is someone to say, "it's alright. I'll help you." Help maybe putting her on to a help line, putting her in touch with someone who can help her financially or emotionally. To set up some sort of a support system, one to one or through an organization, through an NGO. Lot of people don't know that there are organizations to help them. Lot of people don't know that they could find ways of rehabilitating their lives. Lot of people don't know whether they are going to die because their husbands died. So there are ways of helping them cope and if you can as a journalist do that, it is extending your scope of action but why not? Why not, we are all human beings and finally a journalist is doubly blessed with the power of expression and the power of understanding because you cannot write a story unless you understand it.

I also think three things must be observed while reporting on such issues. Empathy has to be used while reporting to evoke empathy in the reader. Information must be given accurately and without bias. If it is a sympathetic bias, then it is fine but there should be no judgment, no bias against a particular community or a particular way of life. The facts have to be checked, rechecked and then stated and there should certainly be no sensationalizing because sensationalism is unfortunately what is the bane of this particular issue. We have done so much harm and created so much stigmas by literally making films out of sorrow by, sensationalizing it to

the point of creating a hysteria about it. We need to bring it down to the level of you and me to the level of a flu epidemic or a malarial epidemic, I think people would then understand it. I think a person dying of malaria is as tragic as one dying of HIV/AIDS. It should be seen in that context that this is what will happen to the family of a person who dies of malaria, this is what will happen to a family whose bread-earner dies of HIV/AIDS. I think, the scenario will change a great deal if the stigma is removed and these are ways in which we can probably help to remove the stigma.

## **Regional perceptions**

Shriram Shridhaye

Maharashtra Times, Mumbai

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We came to know about AIDS in the 1980s when it had started to play havoc in the United States of America and Europe. We, in India, were of the opinion that this was something about which we need not bother. We did not show any curiosity either. Of course, there were some exceptions like the Maharashtra Times, which published an article on AIDS. But we did not get any feedback from our readers. One point that must needs be mentioned is that compared to English papers, language, especially Marathi papers have limited pages. Their priorities are different, because readers prefer to read about the social, political and economic issues. Let me clarify that very few realize that AIDS has a social dimension as well. Naturally the emphasis is given on these areas. Science and technology gets place when something dramatic or different happens. Health has always been given priority but AIDS does not get that priority because no one was talking about it at the official level.

It was years later, around 1989 that the Central govt. announced on the floor of Parliament that there was an epidemic of AIDS in India. I wrote an article on various aspects of the subject and we started to receive many letters from the readers. Many of them were curious to know about the tests, and how and where they are conducted. After that the issue got regular coverage in the language press.

Similarly, the response that a friend Dr. A. K. Joshi and I had written in 1995 on immunology and AIDS especially from the rural areas of Maharashtra, is alarming. The questions normally asked are about the tests confirming HIV infection. Whether all body fluids contain HIV, and can one get infection from sweat and tears. Whether HIV spreads through mosquito bite, if one is HIV positive can he/she get married, is there any medicine in Ayurveda, how safe it is to go for traditional therapy and so on. Many a times questions are of personal nature and asked in good faith. Fan mail is encouraging but every letter that we get makes us sad; as it confirms the wide spread of AIDS.

## **Another point of view**

Rupa Chinai

Times of India, Mumbai

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The Indian Media needs to be more questioning on HIV/AIDS. When I first saw the importance of covering HIV/AIDS and the linkages that it had with a lot of wider issues, I got a lot of applause because I was reporting whatever I was told. But when I started to ask questions invitations dried up and I became person-non-grata. So I got left out of the regular things one needs- invitations to workshops, press releases etc- to keep in touch with issues. This is a disturbing trend.

What I also noticed was the manner in which the entire western Media lampooned the South African President Mbeki because the panel he had set up for the International Conference on HIV/AIDS included people with a different point of view. The western Media blotted them out and so did the Indian Media Surely, journalistic curiosity should have prompted us to meet them and present their point of view?

What they are saying is that HIV is the marker of a suppressed immune system, and that Montagnier and Gallo, the French and American scientists who claim to have isolated the virus did not follow a gold standard that is accepted as the standard methodology for isolating a retrovirus. Thus, while claiming to have isolated HIV/AIDS, they actually took a part of the virus but they did not isolate it, they did not purify it or prove that it can be cultured and replicated. Thus the virus particle contained other cellular debris and this formed the basis of the HIV/AIDS test kits. Such an HIV test can respond to cross –reactions and give a false positive report.

Alternative thinkers are therefore saying that there are 70 different conditions like malnutrition, the common flu, tuberculosis, malaria, even pregnancy in which if you do an HIV test you can get a false positive report. What this means is that you can test HIV positive but the test is actually reacting to a lot of other infections that are there because the HIV virus was never isolated in its pure form.

They are also saying that there are four factors that are leading to immune suppression-antibiotic abuse, recreational drug abuse, anal sex and nutritional stress. This evidence from western scientists seems to ring true to me because I thought it as very well studied.

Nevertheless, I then tried to look at what am I seeing in Mumbai. We are supposed to be living in the AIDS capital of Bombay and I can see two distinct trends. One is that when people who are testing HIV positive receive proper counseling, change their lifestyles and get proper nutrition, access to basic health services and counseling they do very well. The evidence is coming from all corners and we now have patients who tested positive 12 and 15 years ago. The Salvation Army, which runs HIV/AIDS counseling services, for instance reports that of the 900 HIV positive persons they are in touch with only 15 have died from causes of malnutrition and TB.

The other problem concerns two groups - those who are using recreational drugs and those belonging to gay-groups. I think the mistake we are making is that we are giving a lot of importance to needle exchange programs without talking about detoxification and rehabilitation. Telling people to use a clean needle is being seen as an entry point and helps create a feeling of acceptance. We need to go beyond this and give them proper support, through detoxification and rehabilitation. Our public health system is not responding to this need, but the evidence from some NGOs show how successful this approach is. In this context it must be mentioned that an opiate Buprenorphine (a partial opiate agonist) is helping people to get off hard drugs This again is something we should support because what our public health care is doing is putting people straight into cold-turkey.

I would also like to mention that some western evidence indicates that even with condoms, anal sex doesn't give you protection and that it causes toxic shock to the body and thereby leading to suppression of the immune system. Interestingly, gay groups are unwilling to accept this argument. What we are also seeing in Mumbai are discordant couples where one partner is negative and the other is positive and they are not using condom.

We clearly need to broad base our interventions and go beyond condoms, sex education, multi-drug therapies and HIV testing because they have no reality in the wider picture of India. We need to look at issues of nutrition, of access to health care, and sex education. In the Northeast if you ask women their main concern in terms of health, they ask for information on contraception. So irrespective of HIV/AIDS, the desire to know about family planning,

contraception is there but we are not meeting this need and are scaring people by talking about it only in the context of HIV. We don't need to do that.

The other thing I feel very strongly about is HIV testing. There have been numerous cases in Mumbai of people being wrongly diagnosed as

Positive. It just shakes their lives and that of their families. A few courageous souls have come to our office and talked to us about it and we've written about it. But there is no way of knowing at what level this is happening.

The numbers issue has been raised often enough but what is very disturbing is that all available data is coming from the public sector. We are not getting any data from the private sector. So again, if we are taking into account the argument that people are undergoing stress because of nutrition, because of the suppression of the immune system, shouldn't we then be asking what is happening to the better-off population? Whether the same trend in HIV positive tests was being witnessed in the private sector? And are we witnessing the phenomena of people who have AIDS without HIV? I think these are questions we need to be asking.

Moreover, most people go in for just one test, especially the poor, and they are being condemned as HIV positive. WHO says we need 3 tests before we can confirm a positive test. So what are we doing? What is the rationale for HIV testing when it is first of all so expensive and when evidence is showing that you could be living with it for fifteen years with no problems if you're given the right interventions. I think the same messages of prevention can continue without HIV testing.

I would also like to question the scare figures that are being put out of 3.5 million. I think 20 years into an epidemic, we should have field data. If 60 percent of Mumbai's prostitutes are suffering from HIV, many should be dead by now but where is the data? Where are we seeing these large numbers of women dying in Bombay? And where is the death register of India? Surely somewhere there is some authentic record, some indicators of field epidemiology that show a large number of deaths having taken place in say the last 5 years. By now millions should be dead if that is the logic. So where is the death register of India reflecting those huge numbers? Or are we seeing these huge numbers in TB deaths? Surely if you're looking at the graph, they should have risen by now, at least TB deaths. This data is not available to me and when I ask for it, it's not being given.

Questions also need to be asked about the multi-drug therapy. Its not just issues of affordability and cost. I think there's very clear evidence even from the AIDS establishment that it is only relevant for people who are showing clinical symptoms of AIDS, people whose CD4 count may have gone below a certain level. People need to be informed that there are huge toxic problems with these drugs. That once you start you cannot stop, it's a life-long thing and that you have to pay not just for the drugs but the expensive laboratory tests that have to be done every month. I think we have to start informing people, because the drug manufacturers are not providing this information. The AIDS establishment is doing it and I think its only people in media who seem to be asking these questions but they don't get answers.

I for one find it very difficult to write about AIDS when I don't have the answers. I don't know whether I am being honest to my reader. One needs to have a lot of reservation about putting out the kind of stuff that we are flooded with, the press releases and numbers we are sent. I also think there are much bigger killers like TB and Malaria. I think AIDS has to put in that context and its linkages with every other disease. Must be established can be No harm will come to public health if we start looking at the wider issues and no harm can come to AIDS patients if we did so.

## **SONAGACHI – A Review**

Oindrila Mukherjee,  
The Statesman, Kolkata

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I am glad so many here referred to the Sonagachhi Project as a prototype because it really brings several issues to the fore. Here is a project that is being hailed as a prototype that can be emulated in red-light areas all over India. So what should a journalist reporting on HIV in Calcutta do? Should he let it rest on its laurels or does he question the implementations of what has not happened?

In fact, there are two sides to this. On the one hand, there is the Durbaan Mahila Samunai Committee, DMSC, the NGO which runs the sexual health intervention project and they see themselves as quite flawless in their work. Just two days ago I spoke to Mr. Mulal Kanti Dutta, the project director and a doctor associated with the DMSC. Both said the project is working. On the other hand there are NGOs who feel that such targeted interventions are in a way recognizing prostitution. They are also critical of this Project because they feel that insufficient attention is being given to rehabilitation, trafficking etc..

Data from both the DMSC's own studies as well as an external evaluation made in 1999 by the DFID, the funding body showed up some discrepancies. Limitations in the project have also been highlighted in the DFID's evaluation as well and there are some, which the DMSC's representatives themselves point out. Of course, a lot of commendable work has been done as far as awareness is concerned but perhaps it is important to see how it can be bettered and where implementation has gone wrong before taking it further out of Sonagachhi and hailing as some kind of prototype.

The project organizers themselves tend to focus on empowerment and awareness as their achievements and there has been a lot of progress in this area. But I also feel that to some extent this is an attempt to disguise failure in implementation.

According to figures available for six years - 1992 to 1998 - the percentage of Protected Acts is 56.25 percent, which is fairly over half. This is a figure which the DMSC cites most often and they cite it as 90 percent when in fact 90 percent is a combination of sex-workers who always use condoms, sex-workers who often use condoms and sex-workers who use them sometimes. The percentage of sex-workers using condoms always is the one figure I have taken and it is again 50.4 percent, which is half. Moreover, the percentage of clients using condoms went up between '93 and '98 by about 7 percent. These are DMSC's own figures. The percentage of sex-workers who could demonstrate all six steps of condom use was 33% in 1993 according to an external evaluation carried out by an international panel.

The questions we need to ask ourselves is whether given the expenditure and given the fund-allocation, are these figures achieved even assuming that they are reliable which is of course disputed? And are they good enough for the kind of hype and the kind of attention that they receive? If not what more can be done? I think most of us are aware of the limitations because they have been highlighted quite often, condom usage being one of them. There are a lot of people talking about empowerment and things like that and the DMSC report states that distribution of condoms has gone up from 300 a month to 1 lakh a month. Again this is a question of distribution versus implementation. If you ask the peer-educators of the sex-workers at Sonagachhi how they arrived at these figures, not distribution but implementation, they say that sex-workers are asked how many clients they have had on any particular day and how many condoms were used per client per act. The numbers is verified the next day by looking through the dustbins and gutters and tallying the figure. Surely this is a far-fetched way of arriving at any precise data given the fact that there are 6000 brothel-based sex-workers in Sonagachhi.

The '99 report on the evaluation of four partner projects of the West Bengal sexual health project which was published by the DFID however said that 43 percent of respondents always used condoms which is a figure that is even less than half of the figure given by DMSC. So again we need to ask ourselves, is this sufficient for a seven year period. The other limitation is the obvious non-implementation of this condom program. The evaluation itself cites STDs as frequently occurring in sex-workers even in the well functioning condom promoting program and secondly, the high rates of unwanted pregnancies and abortions amongst sex-workers due to the failure to use condoms. The only reason why I'm saying this is because DMSC officials all said that they couldn't improve on the project and that, the project is working. Moreover, according to Mr. Dutta, the expected HIV prevalence to emerge in the fourth point prevalent survey which is being conducted now is 15-16 percent.

When asked about long term goals that they have set for themselves given the huge allocation of funds, they categorically state that it is impossible to set a target considering there is no cure for HIV. If this is the case, can you be absolutely sure that the project is working? What we need to concentrate on is in fact the assessment of high profiled project like the Sonagachhi Project. The State AIDS Society officials themselves have told me that it is impossible to assess the impact of a project like this because the population is largely a floating one. There are about 2000 floating street-based sex-workers in Sonagachhi who are not taken into account in any survey and in peak seasons like Durga Puja, the 6000-8000 figure swells vastly as people come to Calcutta from the districts. The other reason is the difficulty in establishing the incidence of HIV/AIDS especially in a mobile population because a control group would have to be monitored for a year or two, a procedure which may be ethically questionable.. So if impact assessment is not possible, is it not premature to hold it up as a prototype?

These are the kind of questions that one could ask given the fact that here is a model that is supposed to be working as opposed to other cities where there are no models. Interestingly, rehabilitation and trafficking is not a part of this program. DFID officials themselves say that their focus is on HIV/AIDS and not trafficking and rehabilitation, which they contend, are social issues. This is despite the fact that their evaluation quite clearly states that the primary focus of sex-workers themselves is never going to be their health and that social issues should be taken into consideration and HIV/AIDS not be made the focal point.

Other NGOs, say that their programs do not work as well as Sonagachhi because they lack organizational strategy and also because in Sonagachhi the sex-workers have managed to come together and build a forum. This was the starting point and it has helped. It is also argued that if sexual health and HIV was the starting point, perhaps it would not have been so effective. This seems to be the general opinion and yet the DFID says that this can't be our main focus. So somewhere I think there is a contradiction which they themselves are confused about.

So for starters, there is insufficient transparency as far as figures are concerned. Moreover, it is impossible to conduct any kind of impact assessment in Sonaguchi. Only peer-educators, DMSC officials and trained people who are on good terms with the sex-workers, can ask them any kind of questions. So if external evaluations can't be carried out, if the donor body itself makes so many contradictory statements how do we know whether its really working and to what extent it is working?

I'm not disputing the fact that the project is being successful, it has. I have figures here that clearly indicate that awareness that has gone up. But what do we do after that? Do we just haul it up and say this is a great project and everybody else should replicate or do we actually try to figure out whether anything else can be done?

## Regulating the channels

Uma Sudhir  
NDTV, Hyderabad

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I would like to talk about how effective the electronic media has been, the limitations it faces while dealing with this sensitive issue and what perhaps could be done,. But before doing so I would like to bring up something that has been bothering me a great deal concerning the right to privacy, dignity, secrecy and confidentiality. These issues are spoken about, accepted and respected to some extent by the national and more responsible TV channels but what I have noticed is that their regional and local channels that have so much impact tend to be quite irresponsible. In fact, we can't even start to comprehend their reach. There have been so many instances of these channels flashing pictures of the families of people who may have died of AIDS and then after some time, there are reports of the family opting for death instead of social boycott.

Earlier this week there was a report from Warangal in which photographs were flashed by both the electronic and print Media of four children whose father had died presumably of AIDS and the mother who died a few days later. Obviously the reporter must have been concerned about what would happen to these children. Maybe the intentions were noble, of wanting to get them help from somewhere. But who will takes the responsibility for the kind of social stigma that these children will have to face up?

We need to work out some kind of guidelines when we start talking about regulating these channels. At present there is nobody to say what is permissible and what is not. Ashok Pillai was suggesting legal recourse that the people who have been wronged by the media could turn to. But this might turn into a Pandora's Box, something like the Consumer Protection Act for the medical fraternity. It may well be self defeating in its purpose but something like that has to worked out

Essentially the audio-visual media by its very nature has to thrive on pictures. So how then does a reporter tell a story in a medium, which hinges on pictures and strong sound bytes. Both are tricky areas for the audio-visual media. So rather than saying that news-editors are not very sensitive to the issue, its more a case of reporters not being able to visualize how to deal with these important issues. Often, reporters do realize that these are important issues but they don't know how to substantiate stories like this with visuals.

So some kind of sensitization exercise or re-training for people in the audio-visual media could be considered. Perhaps people, not just the national and English Press but all segments of the Media could be trained on how these stories should be handled in the visual media. Because the impact of powerful visuals is very necessary if the report is to have any impact on the viewer

Nigeria I think has done something like that. A segment of journalists underwent training and then they co-opted the editors into it to ensure that their articles made it to the front pages of the newspapers. The journalists were sensitized to the different requirements of the issue and given a basic understanding of what HIV and AIDS is and the terminology that should be used while dealing with this subject.

The other issue concerns the journalists right to information and the right of the source to secrecy. This again calls for sensitivity from the media because this is a very specialized issue that we are reporting on. Of course television users, tends to be very event-oriented and it becomes very difficult in the format of standard news story to be able to deal with issues related to HIV/AIDS. Also, journalists are not by nature specialists so they do not have sufficient

understanding of the subject to be able to make news judgments or even to develop features so that these issues are reported on a consistent basis and not just on the spur of the moment. This is another reason why it is necessary to co-opt editors who would give a push to such issues.

So how does the audiovisual media, report a story if it does not have powerful visuals or sound bytes? Credible sources of information are few, and while there are many organizations working on AIDS whose words are you going to trust? For instance, there are many people who are coming out with cures and promoting them as alternate medicine. How do you deal with something like this? Again, you have to have guidelines on whether you are going to ignore such aspects or are you going to give them some space, some support. It is a very tricky thing.

Besides all this there are the limitations of time and technology and the journalist's own ability to be able to use the tools at his disposal. Some have done this very creatively and they have been able to enhance the value of their stories while protecting individual identities. You can shoot in silhouette or in shadows. Mask the face or mosaic it. This can add value to the story while protecting the identity of the person.

Confidentiality and stigma has also been talked about Again many of the young journalists just come into it the Media. They are not trained and they really don't know how to represent such issues. For a reporter, it may seem like the easiest thing to do to show the faces of the wife and children of someone who has died of HIV/AIDS without realizing that he is violating the rights of the family and the dignity of the individual. The government also tends to be secretive and it often takes on an almost adversarial position. When the press is critical it is immediately assumed that it's the government that is being criticized and all information is blocked out. We have to sensitize the government to be more open with information, to share information with us so that we can together deal with this issue.

With regard to what the electronic media has been doing in this regard. I did try to do a small survey to find out how much of reportage had been done by NDTV on this issue from January 2000. We had ten special reports including a series on India Matters in December 2000. After that there were not more than 40 reports in all over some 400 days. But to NDTV's credit, we covered all the social, economic and medical aspects. But I don't think any of the other channels can even claim to have done that much though this is obviously not sufficient or enough.

Again the question is not whether people, at least in our channel are unwilling to give space for this issue but whether people have the imagination and the creativity to be able to develop features and story ideas connected to the issue. Journalists do not have the know how, they are not specialists and its only a few people who take interest in medicine and health, who report on this. So a broad spectrum of people should be trained to handle such issues. New and meaningful ways must be worked out to reach specific audiences so that the feeling of 'its somebody else's problem' doesn't come across. When we start talking about the problem as something that affects marginalized sections or people with fewer choices there is the danger of even educated people thinking of it as something that the people in the rural areas or people in the slums have to take care of and that they themselves will not be affected.

Again as Rupa was saying, we do need to give space to the multiplicity of ideas and rediscover our own systems of medicine and not just look at western models. We really cannot ignore all this considering the amount of money that comes into this segment. People are also always talking about very, very backdated information. It would be a good idea to have a network of people from all various Media segments who are regularly unformed and updated with data and information from all over the world

# HIV and Indian Media – An AIDs Reporter’s Introspection

G. Pramod Kumar

Special Correspondent, THE HINDU, Chennai

(Presently consultant to UNAIDS, Inter-country Office, New Delhi)

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## **Prologue - *From diagnostic enigma to genocidal frenzy***

As the world observes 20 years of HIV/AIDS epidemic, the global media once again is overheated. The nameless, strange disease that was confined to a small report in a weekly newsletter of CDC exactly two decades and three days ago, has transformed itself into the most intense killer in history.

It is an epidemic that pushes the macabre images of wars, genocides and the mediaeval plague into insignificance. It is an epidemic that has transformed the demographic profiles of nations. It is an epidemic that has ravaged national economies.

And justifiably, it is time to take stock of the situation – New York Times came out with a huge, well-researched and well-written commemorative section and Washington Post had pieces that provoked thoughts and emotions. Newspapers in other parts of the world too remembered to record the occasion meaningfully. But in India, which has the second largest number of people living with HIV/AIDS in the world, what did we do ?

We have five more years to commemorate our 20 years. By then, let’s also be proud that we have the largest number of people living with HIV/AIDS. After the billionth baby, let’s celebrate human misery once again.

## **Just a Whimper?**

Covering social issues in Indian media, obsessively dominated by attritional politics and mass entertainment, can be frustrating. Often, it is soft, stereotyped and journalism of convenience. For the popular media, that measures truth in terms of what is expedient and what is popular, issues like education, health and social development are as respectable as space fillers while statement wars and entertainment industry kitsch become headlines. Of course, there are a few exceptions. In fact, brilliant exceptions.

But when HIV walked into this scene in 1986, there was an arousing welcome. The disease of the West and Africa instantly grabbed headlines and space. It was what the mainstream media wanted – popular and expedient. There was shock, fear, drama and human misery that triggered wild imaginations. Most of the time, they were sensational, speculative, prying, insensitive and irresponsible. Like in the rest of the world, HIV, to begin with, was an issue of social deviance.

Fifteen years later, we see HIV everywhere. It is there in our own drawing rooms, public and private places and right in our midst. We realise that this is truly an epidemic. 3.8 million is no joke and in another ten years, it can breach even adventurous projections. Let’s not forget that the actual figures of global prevalence today are far higher than the projections experts made in 1991.<sup>1</sup> As writer-journalist Sidhardh Dubey notes, 300,000 deaths every year is 20 times the number of people who died in Gujarat earthquake.

But its presence in Indian media, at best can be described feeble. In the American media, it has made a tremendous come back since the early 90s and remains a top priority. Media in Africa too takes it to the main pages. But for us, it is still an issue that can be ignored conveniently. We repeatedly fail to realise that mainstream media is a major tool for bridging the epidemic and everything associated with it, ranging from the very basic scientific facts to the collective and singular efforts to handle it, and the people. It is the cheapest, or free, tool for IEC.

Understanding the dynamics of the media in handling public health issues like AIDS is crucial on many areas like shaping the opinion of society, addressing the specific needs of specific groups or setting the agenda of policy makers, governments and even the international agencies.<sup>2</sup> For instance, a pilot study by Mr. B. Westwood of the Queensland Centre for Public Health in Australia on “Public health reporting and the media” had proposed “that a better understanding of how newspaper reporting deals with health issues is of great importance to public health professionals. It may help utilize the print media to promote information on public health issues to the population in a positive and attention-catching manner”.

Media’s role is also crucial from the point of view of access to information and HIV vulnerability. It has been clearly established that lack of access to information is a major reason for social marginalisation and HIV-vulnerability. As AIDS researchers Thomas Mann and Daniel Tarantola said, “personal vulnerability will be difficult to reduce until the critical information is made available”. For instance, 50,000 years ago, it was some clever piece of information that helped early humans survive, while the Neanderthals, which coexisted with them perished. There have been innumerable examples, ranging from Tianenmen to Ethiopia, to show how Television, mobilized global responses to emergencies. Media, thus, is an indispensable tool for survival too.

As many journalists covering AIDS in India have realised, it has not been easy to sustain the interest on a single disease for such a long period of time. Starting with the shock value of the news-break, as a reporter, I think we have exhausted most of the possible angles, without creatively using even a fraction of their potential: tragedy, human misery, women, children, drama, care, quacks and occasional sob stories. Interestingly, the early media coverage had set much of the tone, the terminology and metaphorical conventions that still operate while talking about AIDS (hapless victims, AIDS patients, AIDS victims and those images of fear).

Travelling with the epidemic has taught me that HIV is just the symptom of a graver, multidimensional epidemic that is composed of endemic poverty, social and gender inequity, myths on sex and sexuality, cultural dogmas and social marginalisation. Everywhere, whether it is in the underbelly of Manhattan or sun-scorched sub-Saharan Africa, it is the marginalised – minorities, women, illiterate, poor and so on – who is affected. At times I even think that the poverty virus has mutated into HIV. Thus covering HIV, in fact, is equivalent to covering a wide spectrum of social issues. HIV is not just a health issue, but a deep-rooted social issue. It is an economic issue, it is a political issue, it is a human rights issue and so on. Viewed from different perspectives, HIV gives never-before kind of opportunities to look at the inequities in our society. Let’s use it.

I have realised that HIV/AIDS offer enormous opportunities to write about taboos that had not been possible before. AIDS coverage brought from the closet, issues like sex and sexuality, reproductive health and marginalised populations like drug users, sex workers, homosexuals and so on. Let’s exploit it.

HIV/AIDS also is an indicator of our public health burden and related issues like access to treatment and public health infrastructure. It gives us new opportunities to look at our obstinate companions like tuberculosis, sexually transmitted diseases, fungal and bacterial infections, cancers and so on. The access-to-drugs issue raises the more fundamental issue of primary and secondary health care. Let’s look at them with fresh impetus and insights.

HIV/AIDS has given us powerful glimpses of human resilience, compassion and activism. People living with HIV/AIDS, people managing HIV/AIDS programmes, people running NGOs etc are telling examples of human will, responsibility and compassion.

And finally, HIV/AIDS has given us brilliant pieces of writing and art. Writers like Andrew Sullivan, Abraham Verghese and John Cogen and movies like “And the Band Played On” and “Philadelphia” would not have been possible, but for the epidemic.

## **Epilogue – will we pay for our inaction?**

We are living with an epidemic. An epidemic is an extraordinary situation. It demands extraordinary efforts.

The HIV epidemic warrants a total paradigm shift and the media is the cheapest and most effective tool to catalyse it.

Let's introspect: media sets the agenda for people, who sets the agenda for the media?

Otherwise, let's wait till 2006, when the epidemic will turn 20 in India.

## **The two worlds of HIV/AIDS**

Kalpana Jain

Special Correspondent, Times of India, New Delhi

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I think Rupa Chinai is absolutely right when she questions the whole HIV/AIDS scenario and asks what is the reality? Because we don't know the reality. In recent months I have been travelling around the country. I have been to all the high prevalent states and also to Bihar to see the situation. Is it a low prevalence state or a high prevalence state as is being claimed? Without taking a stand on the issue of HIV/AIDS vis-a-vis dissidents I would say that I saw an enormous problem. I don't think any of the policies are working and I think money is being completely wasted. As I went around came across villages with pockets of families who were affected by the epidemic. This I think is particularly dangerous because it is increasing in places where they are not even aware of the situation. One activist who was working in the area said that he takes care of 100 families, which in fact means 200 people because their families also go down with it.

And if it is not HIV/AIDS what is it because the symptoms everywhere are similar. The same kind of brain infection, the same phenomena of entire families affected by it and the old people left out of it. And if it is about immuno-suppression then why is the old not going down with it? Why just the young people in families and children? Certainly something is happening, something is going wrong. And if it is not HIV/AIDS then someone needs to look at it and say what it is all about.

I have been asked to speak on the constraints of writing on this issue. And though I have been looking at HIV/AIDS since 1993 the enormity of the situation hit me only when I started visiting care centers in various parts of the country. In Panchgani I saw the sort of numbers I had not seen before. And after talking to men, women and children affected by the epidemic the trauma was so intense I wanted to keep a distance from the issue. In fact, as a journalist you are supposed to maintain distance from what you see and what you are reporting but it did affect me and leave me with very complex questions to deal with. For one, how do you stand by the bedside of a person who has just a few days more, looking for a story. There are relatives standing around with folded hands. They think you have come with some kind of cure, some kind of hope, something to give them and you don't have anything to give.

At the end of the day it leaves you wondering what your own role in it and what you are giving even as you are taking a lot from them at that point of time. So, the last six months have been a transforming experience for me and the way I have been dealing with it earlier is very different from the way in which I am dealing with it now. Moreover, while it can be seen as a complex problem, a social problem with many facets at the end of the day it boils down to just two issues- sex and death.

What also makes it really difficult is that there are two worlds emerging in HIV/AIDS. The world that is aware and has learnt to deal with it through nutrition, counseling, drugs so that the affected

can live a normal life for 12 to 14 years. There is also the world of those who have no access to any of this. Of people who are dying in six months, eight months, maybe a year. Then you don't really know how to handle the situation. You don't know how far you can go in your questioning. Whether they are aware of what they are suffering from, whether they know the implications of the problem. In Andhra Pradesh I met a woman who was seven months pregnant and had been married for a year. The counselor who took me there told me she was well aware and that she knew about it. But when I asked her what it meant for her life, she started to cry. So you really don't know what to do then. At one level you are being a journalist but at another level how do you handle such a situation? Because the story becomes insignificant and the human being in you that takes over and you don't really ask the kind of questions that you want to ask at that time.

And it is more difficult when you have to deal with children because in a way you are making them replay their lives. In Bangalore I did speak to one child. It was traumatic for him to talk about how in school his friends were harassing him and the kind of trauma he is going through. Then in Andhra Pradesh a young women who had been widowed just five days earlier and had three little children took me to the dump where her husband had been left. It was a proper dumping ground. It was stinking and there were dogs and pigs around. These are the images that I have in my head. So, even if you try to be very objective somewhere you do start taking sides and saying I am convinced this is HIV/AIDS, this is the an epidemic that we are getting hit by.

Moreover, when I started this work the issues really were about the ethics of reporting , confidentiality and not giving names. But after having been around the issues of ethics and confidentiality remains but I don't know how far it is relevant to stick to the same terminology of people living with HIV/AIDS and not people not being victims of HIV/AIDS. I think they are victims because if you look a at the long queues of women in Pune and elsewhere or young widows or widow groups how can you refer to them as living with HIV/AIDS? So my whole approach to the issue will change, is bound to change.

As I went along I also realized that one has to come to terms with a lot of one's own prejudices, upbringing and sense of morality. When you are dealing with these issues we maybe journalists but we are a part of the same society and can be judgmental when we look at these issues.. So one of the first things I did was to get out of this judgmental mode because I found people clam up when you question them on how they got it. Some of them wanted to clarify that they had not got it through the sexual route and that they had got it through blood or whatever.

But at the end of the day I would say that the Media is to blame to some extent for sensationalizing the issue. And we are guilty of it all the time especially in states where there is very little awareness. In Bihar you find that it is not just the people who react to it in a negative manner but the doctors who tell the Media that so and so is affected and the Media reports it resulting in a lot of stigma and discrimination of the person and his family. We really need to educate the entire Media and learn from our mistakes and experiences. What I also found very interesting is that when I traveled earlier people liked to show me the numbers but this time it was the other way round. They wanted to hide the numbers and only show places where awareness and condom programs were being done. So there is an attempt to hide numbers which we should be careful about as also NGOs who present inflated figures. Because when you start questioning them they get upset and start questioning your motives for collecting information. I have never had to address questions on my motives while working on other issues but with HIV/AIDS people need to be convinced of your motives and why you are working on it because there are so many vested interests.

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