

*Report of*  
Dissemination meeting of ILO Study  
on  
"Socio-economic Impact of HIV/AIDS on People  
Living With HIV/AIDS and their Families"

14 October 2003

Gulmohar, India Habitat Centre, Lodi Road  
New Delhi

International Labour Office, New Delhi

## List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti Retroviral Therapy
DNP+	Delhi Network of Positive People
GIPA	Greater Involvement of People Living with HIV/AIDS
HIV	Human Immune Deficiency Virus
IEC	Information Education and Communication
ILO	International Labour Organization
INP+	Indian Network for People Living with HIV/AIDS
MNP+	Manipur Network of People Living with HIV/AIDS
NACO	National AIDS Control Organisation
NCAER	National Council of Applied Economic Research
NGOs	Non-Governmental Organizations
NLI	National Labour Institute
NMP+	Network of Maharashtra by People Living with HIV/AIDS
PLWHA	People Living with HIV/AIDS
PWN+	Positive Women's Network of South India
UNIFEM	United Nations Fund for Women
VCTCs	Voluntary Counselling and Testing Centres

## **List of annexure**

Agenda of meeting

List of participants

**The** ILO India AIDS project released the findings of its study report ‘Socio Economic Impact of HIV/AIDS on People Living with HIV/AIDS (PLWHA) and their families’ on 14 October in New Delhi. The report was released by Mr Baleshwar Rai, Additional Secretary, Ministry of Labour, Government of India, at the India Habitat Centre. Among those present on the occasion were Mr Uday Kumar Varma, Director, V.V. Giri National Labour Institute, Dr Sadhana Rout, Joint Director (IEC) of the National AIDS Control Organisation, Mr K.K. Abraham, President, Indian Network for People Living with HIV/AIDS (INP+) and representatives of state networks of positive people. Several NGOs working in the sector such as Chelsea and Sahara, representatives from various embassies and the corporate sector also participated in the meet (agenda and complete list of participants annexed).

The proceedings were kicked off by Mr Maurizio Bussi, Deputy Director of the ILO, who stressed that the core principle behind the programme was the greater involvement of people living with HIV/AIDS (GIPA). “We have given a formal commitment that PLWHA are with us in ILO’s work on HIV/AIDS and the world of work,” he said, stressing that the study was but just a beginning.

A short but powerful film clip of an HIV positive woman speaking out about her experiences at a labour meet in Geneva reinforced the message that the involvement of the affected people can strengthen such programmes. Her underlying message to all HIV positive people: “Don’t be submissive, don’t give in.”

Mr S.M. Afsar, National Project Coordinator of ILO India’s AIDS Project, who presented the study findings, thereafter, too stressed how the PLWHA have a huge power within them, and if they speak out it can create a powerful impact. The study’s greatest strength, he felt, was that it had been conducted by the affected people themselves. The ILO provided technical assistance empowering the PLWHA to conduct the study. He hoped that the findings of the study, which had taken nine months to be completed, would give national and international agencies working in India on HIV/AIDS a concrete evidence to strengthen their efforts, particularly in the area of policy advocacy and care and support. ILO valuable

inputs in strengthening its AIDS programme. “It was a learning experience for ILO, also as by doing this work with the networks of PLWHA, we actually got an opportunity to have a closer look at the sufferings of PLWHAs,” said Mr Afsar. Further, Mr. Afsar said that though the process of building capacity of networks for undertaking this research work was found to be very useful but the findings are so depressing that one can't be happy presenting this scenario. He cited the case studies of affected individuals in Maharashtra, Tamil Nadu, Delhi and Manipur, which showed that stigma and discrimination was still rampant aggravating the difficulties of the positive people.

The highlights of Mr Afsar's presentation are as follows:

- The study objectives were threefold: to get an understanding of the overall experiences of the people living with HIV/AIDS; to study the stigma and discrimination associated with the disease; and to study the socio-economic impact of HIV/AIDS, especially on women and children.
- The geographical focus of the report was the three high prevalence states of Manipur, Tamil Nadu and Maharashtra. Delhi was included as it attracts a large number of migratory workers. The participation of the Positive Women's Network of South India was important as it added a women's perspective to the issue.
- 92% of the respondents were in the 19-40 age group. While the mean age of the respondents was 32.05 years, the average age of men was 33.5 and women 30.1 years. The youngest affected men were in Maharashtra while Delhi had the youngest women respondents. People go to Maharashtra in search of work at a young age, so perhaps that explains why Mumbai had the youngest respondents.
- A majority of the respondents (69.86%) had received education up to school level. However, illiteracy was more among women (17.21%) as compared to men (11.18%), thus highlighting that they were at higher risk of economic insecurity.

- Stigma and discrimination associated with the illness continues to be high. Nearly 70% of the respondents faced discrimination – most faced it from the family itself, followed by health care centres.
- Of the total around 90% of women in "married", "separated/divorced" and "widowed" categories indicates that the transmission of HIV among women is predominantly with the institution of marriage. As far as acceptability was concerned, majority of participants was living with families. It took time for families to accept them.
- The data on the discovery of HIV status revealed that women are getting infected at a younger age as compared to men. Their mean age at the time of testing was 24.4 years as compared to 28.03 in the case of men. About 70% of the respondents received pre-test and post-test counselling. Counselling was mainly done in government hospitals and not in private hospitals. Around 78% of those who had taken precautions after knowing their status had received counselling showing the significance of counselling.
- Only 30% of those affected were employed in the private/public sector. The unemployment was highest in Manipur. Six percent reported discrimination at workplace. This could be higher as many did not disclose their HIV status to employers for fear of losing job. Denial of promotion, voluntary retirements were some of the forms of discrimination. Discrimination by co-workers was also cited as main reason for changing jobs frequently. Respondents also reported that confidentiality norms are being violated.
- The impact on incomes was severe with reported income loss averaging around Rs 7,500. The impact on women was especially severe, as they had to take additional jobs. 44% women reported loss of income while taking care of the ill.

- Children too faced the brunt of the situation. 17% of children had to take up petty jobs to take care of the household exacerbating child labour. 5% were withdrawn from schools.
- With incomes going down and expenditure on medicines rising, there was a change in pattern in spending. Spending on education and entertainment came down revealing that the impact of the illness on education.

Mr Afsar then summarised the future concerns of the PLWHA who wanted affordable treatment, were worried about the well being of their children, expressed a desire to have a regular income in the households and ready access to treatment.

The key recommendations of the study are:

1. Treatment support for PLWHA at subsidised costs.
2. Income generation programs needed for PLWHAs, particularly meaningful GIPA.
3. The ILO Code of Practice on HIV/AIDS needs to be adopted at workplace.
4. Advocacy initiatives to keep PLWHA in employment. The corporate sector also needs to be sensitized to HIV/AIDS.
5. A health insurance policy for the affected.
6. Strong legal policies.
7. PLWHAs to be engaged as peer counsellors.
8. Training of ESI doctors in HIV cases
9. PPF and gratuity to automatically be made available to the spouse of those affected by HIV/AIDS.
10. Care centres for the support of the affected children.

Mr K.K. Abraham, the president of the INP+, in his presentation described the process of the study as very empowering. He stressed that the recommendations suggested in the report have to be adopted. He added, “our own network experiences show that early detection of HIV is not happening. Early detection can make changes in people living with HIV/AIDS”.

In his brief presentation he stated the goals, objectives and various activities of INP+. Mr Abraham was also concerned about the availability of anti-retroviral drugs, which he said was his goal as INP+ president. For this, he said, we need to make structures for advocacy. “We are trying to constitute an ARV fund like the Kargil fund to access anti retroviral drugs,” he revealed.

He also informed about INP+'s effort in direction of setting up of a positive speakers' bureau through which affected people are being trained to articulate their experiences, reaching out to schools, colleges, workplaces and the public at large. This would go a long way in removing stigma and discrimination associated with the illness.

Commending the work done by the networks and the ILO, Dr Sadhana Rout of NACO said: “In this (study) we have for the first time an articulation of the needs of the People living with HIV/AIDS.” The study also showed that “we are moving beyond our tokenist statements on GIPA,” she said, adding: “We are happy that this (the report) has come out from the positive peoples networks. When we talk of involvement of positives it is necessary, but the question is who will build capacity? ILO has been doing it. UNIFEM has also been doing it and so has the Ministry of Labour. The mainstreaming of HIV positives is a well-documented policy of NACO.” Added Dr Rout, “We all agree that HIV is a development issue. Here's one more evidence that it is a general issue.”

Dr Rout was also concerned at the impact of HIV/AIDS on women, as revealed by the study. “Women are at greater risk. The gender dimension of the epidemic is brought out very clearly by the study. We need to urgently ask ourselves, what kind of interventions are needed,” she stressed.

Coming to the recommendations, Dr Rout had some positive news to convey. She said that NACO was already moving on implementing the recommendations in the right direction. “As far as stigma and discrimination are concerned, the government is motivating all sections. It is trying to tell everyone that a societal response is necessary. We do have a communication campaign but a greater societal response is needed. Also, the government is

talking more and more about ARVs. We have initiated a dialogue with pharma companies to lower the price of drugs,” said Dr Rout.

“The VCTCs (Voluntary Counselling and Testing Centres) are so far only there at the district level. But there is already a move to engage PLWHA as counsellors. The PLWHA are already members of many of our committees. As far as income generation goes, in Gujarat the micro credit scheme has been tried out and has a good potential for replication,” concluded Dr Rout.

Mr Baleshwar Rai while addressing the gathering commented: “The study will give us thoughts to react and devise our strategies for the future. It is surprising to note the extent of stigma and discrimination prevailing among women.”

The deteriorating economic impact on the PLWHA is also shocking, said Mr Rai. “We will do a mistake if we don’t act now. India has 4.58 million people living with HIV/AIDS by 2002. The number is increasing and now we are about 10% of the global HIV population. Six states are high prevalence states. He said, "to my mind, the report gives us one message very clearly and that is HIV/AIDS is a real threat, it has started showing adverse effects in India. We shall make mistake if we don’t take these findings seriously and strengthen our response to HIV/AIDS". The epidemic is becoming a serious problem for the country. We need to learn from the Sub Sahara African countries where most of the younger generation is affected by the disease,” said Mr Rai.

Mr. Rai said, "if we don’t upscale our efforts of prevention and control, we shall be heading towards disaster. We need to learn from the experiences of some of the worst affected countries in sub Saharan Africa. Prevention and care go hand in hand. We should not be found lacking on the front of care and support. I am told that NACO is taking several steps in this direction. But NACO can't do it alone. It calls for a multi-sectoral effort because HIV/AIDS impacts all the sectors". He commended Mr. Abraham for the suggestion of a National Fund where all can contribute so that the government's AIDS programme could be further strengthened.

The ILO estimates that out of 42 million people living with HIV/AIDS 26 million are workers. In India, nearly 90% infections have been reported from the most productive 15-49 age group. This is enough to indicate that HIV/AIDS has become a crucial workplace issue. The AIDS Policy of Government of India recognizes this while stressing that organized and unorganized sector of industry needs to be mobilized for taking care of the health of the productive sections of their workforce.

He said, "we should create an environment where a person with HIV/AIDS can live comfortably and not worry about where the next rupee is going to come from. Perhaps a trust can be formed that could take care of the needs of PLWHA," he suggested.

Ministry of Labour, Government of India is aware of challenges that HIV/AIDS poses. We are working closely with the ILO to strengthen the world of work response to HIV/AIDS in India. Two of our institutions, National Labour Institute and the Central Board for Workers Education have integrated HIV/AIDS into their programmes. We are working closely with NACO, the trade unions, employer's organizations and enterprises under the ILO Project. The project has developed some very useful materials for training and advocacy, which can be of immense value in the national effort.

Mr Rai revealed how the government had drafted an unorganised sector workers bill where medical and insurance facilities will be provided by concerned ESI hospitals. "That's a very positive thing that's happening. The ministry of labour is aware of the challenges. The Central Board for Workers Education and the National Labour Institute are working closely with NACO on this". In his concluding remarks he congratulated the PLWHA networks and the ILO for having conducted such a good study, which not only gives evidence but also provides several points for action. He hoped that the findings of study will be used by all stakeholders while developing and implementing their HIV/AIDS programmes.

He said. "as Chairman of the ILO AIDS Project Management Team, I am particularly impressed by the fact that People Living with HIV/AIDS are involved at every stage. They are represented in the Project Management Team as well all training and advocacy efforts. Their involvement can be extremely useful in prevention as well care programmes. I am glad

to see that this study was also conducted by the networks from the four states and they are present in today's release function."

Mr. Ravi Subbiah, Programme Officer, ILO, proposed vote of thanks to all participants before breaking for tea.

Mr. Uday Kumar Varma of the V.V. Giri National Labour Institute kicked off a panel discussion that began with presentations from the various representatives of the state networks of positive people. Mr. Varma described it as a bold move to assign the study to people living with HIV/AIDS because, he said, even people in research would see the difficulties involved. But that's where the disadvantages end, he felt, because their own experiences will give corroboration to the findings.

Mr Varma went on to add: "The study also raises some questions and gives recommendations. The problem of HIV/AIDS is well defined. The challenge then is how do we look at the people who suffer from it. The perspective coming from there, as it does so in the report, is the right one. Across all policies you should consult those for whom you make it."

Ms. A. Padmaja, presenting on behalf of the Positive Women's Network, a Chennai-based organisation introduced her network as one whose goal was to improve the quality of life for women in India.

While most of the findings broadly corresponded with other state networks, in Tamil Nadu, 53% of the respondents in the state said they had faced no discrimination.

However, Ms Padmaja said that the fact that families are the ones that practise discrimination the most was shocking, given the trust placed on them by the positive people. Ms Padmaja also expressed dismay at the finding that 68.1% of the respondents had not received any counselling at the time of detection.

She said that the data clearly revealed the inability of women to negotiate their basic reproductive rights or for that matter their human rights. She particularly cited the case of a woman whose spouse's provident fund had not been given.

A positive development shared by Ms Padmaja was that in Tamil Nadu, PLWHAs have been placed as peer counsellors in VCTCs.

In a highly charged presentation, Mr Naveen Kumar, former president of the Delhi Network of Positives and Deepak Singh of the MNP+ spoke out against the use of the word AIDS in various poster campaigns. "We are HIV positive – and we are years away from contracting AIDS," said Mr Kumar expressing indignation and anguish at the simultaneous use of HIV/AIDS in various commercial campaign. Here Naveen complimented ILO for giving correct information about how HIV (not AIDS) spreads through their posters.

While the key findings more or less matched those of the other networks, the discrimination faced was far higher, with 88% in Delhi and Manipur coming up against it. And, after the family members, it was at the health care centre that the HIV positives encountered discrimination. "When we say health care centres, it's not the doctors but the ayahs, the nurses and ancillary staff, which show maximum discrimination," said Mr Kumar.

Citing the study findings, which showed that most of the respondents took precautions to protect their spouses and children, Mr Naveen Kumar said that the data revealed that HIV positives showed highly responsible behaviour. "We are responsible people," he said proudly. Mr Varma made the point that early detection was thus important and the awareness campaign should focus on it.

Mr Manoj Pardesi of the NMP+, the Positive Network of Maharashtra started his presentation by thanking ILO for the 'trust' shown in PLWHAs for doing this research work. He also underlined that the process was very empowering for PLWHAs as it built their capacity. Further he said that social change doesn't happen very fast, but if we get together we can make it happen. He described the network of People Living with

HIV/AIDS as a movement. His key concerns were that often policies were made on paper but there was no implementation on ground.

Mr Pardesi also said that at NMP+ they had moved beyond the term GIPA and was now talking of GIEPA – the greater involvement and empowerment of the people living with AIDS. Mr Pardesi concluded with a strong plea that the study should not be consigned to some dusty library shelves but its findings should be used when policies were being framed. Mr Afsar assured him that the ILO, for one, would certainly incorporate some of the findings in its training modules to ensure its dissemination far and wide.

During the question and answer sessions, Dr Ramamani Sunder of the NCAER asked the network presidents to describe how they enrolled new members – her concern was that the membership of networks was so low when compared to the huge number of HIV positives in the country. Mr Deepak Singh pointed out the difficulties in enrolling new members in Manipur as injecting drug users had to contend with not only the underground force but also the police and thus lived in perpetual fear. Thus they were afraid to come out. He also said that the government counsellors were not particularly approachable, presenting a forbidding image in their ties and suits. Instead, if counsellors were appointed from the positive people themselves, it would perhaps motivate more people to come forward. Mr Singh and Mr Kumar also felt that the government should not practise forcible testing but leave it up to the people to go in for voluntary testing.

Dr S.M. Akolkar from Bajaj Auto sought clarification on the sampling of the study and felt that if confidentiality of HIV status could be maintained people would come forward to get themselves tested. Sharing his experiences at Bajaj, which has an intensive HIV/AIDS awareness programme for its workers, he said that out of 8,000 workers only 200 came forward to avail of the free testing facility, showing that most were afraid to come forward. Responding to that, Mr Pardesi said that the VCTCs could play an important role here. Mr. Afsar suggested that Bajaj Auto could linkup with their PLWHA network in Pune.

A sombre note was introduced in the proceedings when Mr Pardesi revealed that there had been 72 deaths in Pune alone last year. Mr Deepak Singh said that the figure in Manipur was

even higher – with 100 deaths. As Dr Akolkar commented, “HIV/AIDS is an iceberg phenomenon. We know the tip, we do not know what is under.”

Some queries were raised by the audience on the sampling size, which at 292 was felt to be very small. Mr Arun Baroka, Project Director, Delhi State AIDS Control Society, raised a question on the methodology used during the survey, pointing out that the study covered barely a fraction of the 4-million estimated HIV positives in the country.

Responding to this Mr Afsar said the limitation of the study was on it was confined to PLWHA membership and two, more than 90% estimated PLWHAs do not know that they are infected and those who know don't come out openly with their status due to stigma and discrimination. Further he said, the sampling was purposive and that the quantitative information was substantiated with the qualitative information gathered during focus group discussions. In any case, as Mr Varma summed up, the whole study has to be viewed not from the perspective of statistics but as a qualitative account. He felt that even if the number of respondents had been more, the response would in likelihood have been the same, given the uniform reactions that poured in from all the states.

Ms Tripti Tandon of the lawyers collective described how a draft law on HIV/AIDS was in the process of being framed. As of today, the private sector can do what it wants, but this law could ensure that workers are not stigmatised in an office, she said.

Summing up the session Mr Varma said, “Can't we think of having only positive people as counsellors?” On the issue of stigma and discrimination, Mr Varma felt optimistic as he pointed out that the women from Tamil Nadu reported very less stigma – over 53.5% said they had not faced stigma. And even though maximum people had faced discrimination from their families, he said that the encouraging finding was that despite initial rejections, in most cases the families had come forward to actually support the infected. He concluded by saying that the positive people themselves are playing a very powerful role as they are coming out in the open.

**Dissemination of Study Report  
"Socio-economic Impact of HIV/AIDS on PLWHAs  
and their families"**

14 October 2003  
Gulmohar, India Habitat Centre, Lodi Road  
New Delhi 110003

Agenda

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|------------------|--|
| 10:00 - 10:10    | Welcome address by Mr. Maurizio Bussi, Dy. Director, ILO   |
| 10:10 - 10:15    | Release of report by Mr. Baleshwar Rai, Additional Secretary, Ministry of Labour, Govt. India  |
| 10:15 - 10:35    | Presentation on key findings of the study by Mr. S.M. Afsar, National Project Coordinator, HIV/AIDS Project, ILO   |
| 10.35 - 10.45    | Brief statements by:<br><br>Mr. K.K. Abraham, President, Indian Network for People Living with HIV/AIDS (INP+)<br><br>Dr. Sadhana Rout, Joint Director (IEC), NACO |
| 10.45 - 11.00    | Address by Mr. Baleshwar Rai, Additional Secretary, Ministry of Labour, Govt. of India   |
| 11.00 - 11:05    | Vote of thanks by Mr. Ravi Subbiah, Programme Officer, ILO AIDS Project  |
| 11:05 - 11:25    | Tea break  |
| 11:25 - 12:05    | Panel Presentations and discussions, Chaired by Mr. Uday Kumar Varma, Director, NLI<br>(Brief presentations by networks: - DNP+, PWN+, NMP+, & MNP+)               |
| 12:05 - 01.15    | Open discussion  |
| 01.15 - 01.30 PM | Concluding remarks by Mr. Uday Kumar Varma.<br><br>Vote of thanks by S.M.Afsar, ILO  |

**DISSEMINATION MEETING**  
*OF*  
**STUDY REPORT “SOCIO-ECONOMIC IMPACT OF HIV/AIDS ON PEOPLE  
LIVING WITH HIV/AIDS AND THEIR FAMILIES”**

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