GHENNAI AGENDA

ON HIV / AIDS

An initiative to break the silence in TamilNadu



Initiated by

Tamilnadu State AIDS Control Society Chennai **Contributed by**

NGOs/CBOs Research Institutions Media Positive Network



THE DURBAN REFLECTIONS

Tamil Nadu State AIDS Control Society organised a meeting on the 31th July, 2000 for the participants from Tamil Nadu of the AIDS 2000 International Conference held in Durban, South Africa.

The participants who attended the Conference comprised of persons from various disciplines working in the field of AIDS in Tamil Nadu. It was represented by the Ngos, press, people living with AIDS, persons from funding organisations, specialists from HIV/AIDS treatment and counselling centres to name a few:

The welcome and introductory remarks were made by Dr. K. Gopal, IAS, Project Director, Tamil Nadu State and Control Society. The main purpose of this meeting, according to him, was to invite the participants to share the perceptions and experiences with reference to the Conference, the present and future MIV/AIDS preventive and control machanisms in Tamil Nadu through transforming the strategies from concepts into action to such the conditions in Tamil Nadu.

The sharing of the views of the participants revealed that each one had special experiences that were unique. Following this, there were discussions on the relevance of adapting some of the methods in Tamil Nadu. The general perception was that Tamil Nadu needed specific interventions to tackle HIV/AIDS more effectively. This meeting served as a common platform to voice this and evolve certain strategies.

The Conference ended on a positive note with the delegates unanimously proposing that action needs to be taken based on common concern. The areas of concern have been presented in the form of resolutions.

Mr. Hariharan of 1cwo, proposed a vote of thanks to the participants for having attended the meeting.

GLOBAL EFFORTS

The city of Durban in South Africa, the host of XIII International Conference on HIV/AIDS has generated sufficient enthusiasm and energy among the participants who attended the Conference. The conference had become the focal point for the convergence of the thoughts, concepts and also innovative models in the field of control of HIV/AIDS, the most serious public health problem challenging the developmental processes and survival of human race in advanced and under developed countries. More than 12,000 participants from all over the world, across 178 countries and from different sectors such as, Research, Planning, Health Administration, NGOs, Media, Community and policy, have made the conference a grand success. The Conference has also motivated the Governments all over world to concentrate on effective and result oriented prevention strategies, appropriate drugs or vaccine to tackle the menace of HIV/AIDS.

TRANSMISSION OF EXPERIENCE INTO ACTION

About 200 individuals from India participated in the XIII International Conference held at Durban, out of which 30 representatives were from Tamil Nadu. This reflects on the determination of the State and participants to combat the infection hazard which is spreading very fast across all the starta of the community. Representatives from the State Government, Research Institutions, Non Governmental Organisations (NGOs) and Community based organisations, (CBOs), Media and persons living with HIV/AIDS attended the Conference. With an intention to utilise the information available, it was decided to replicate the experience and concepts in Tamil Nadu, with suitable modifications according to the prevailing conditions. Tamil Nadu State AIDS Control Society (TNSACS) has taken a lead to invite the participants of the conference to evolve and come up with the "Chennai Agenda" for the State. This reflects the strategic role to be played by different partners and their responsibilities. The issues, which are applicable to the State were identified by this group which comprises of the views of all the stakeholders. The Chennai Agenda declared by the participants is considered as an optimistic move to bring the partners together to transform the thoughts into action for better implementation of the HIV/AIDS prevention and control programme in Tamil Nadu.

SHARING THE RESPONSIBILITY

Several issues were focussed in the Chennai meet organised at TNSACS. The present epidemic scenario in the State, the delivery mechanisms developed so far to tackle the epidemic, the role played by the State Government, research institutions and NGOs, and the several related issues were deliberated upon before arriving at a consensus on the common agenda.

The Chennai agenda fixes the responsibility on the Government and the partners to achieve the common objective, to reduce the prevalence of HIV/AIDS in Tamil Nadu. The priorities are expected to be incorporated, wherever possible, in the strategies of the Government, the media, the NGOs, and research institutions.

RESOLUTIONS:

- Media shall be involved to create awareness and behavioural change and to mould a favourable social atmosphere in the state. This will facilitate an environment free from social stigma and discrimination. More media representation shall be given in national and international conferences to get many more sensitized and to contribute to the prevention efforts.
- There shall be coordination of efforts among the different States to ensure uniformity, and to avoid any gaps for the wellbeing of all the States and the nation. The upscaling of projects, replicating and adopting intervention models of Tamil Nadu to other States shall be given due attention.
- Constant coordination of different agencies involved in prevention and control activities shall be ensured to have access and flow of information on experiments, concepts, and success stories of different stakeholders and the Tamil Nadu State AIDS control society shall take the responsibility for the same, for the benefit of every partner.
- Political will, and the active involvement of local Government, and the policy makers shall be mobilised to give a real thrust to the anti HIV/AIDS efforts and to make the programmes more acceptable and reachable to the communities in the State.
- Efforts shall be focussed towards strengthening of the network of positive people and also linking the groups for better results. Strategies shall be evolved to eliminate social stigma and discrimination against the affected, in consultation with people living with HIV.
- Informed consent of the individuals shall be made mandatory for all HIV testing and appropriate counselling methods and practices shall be followed. HIV counselling and testing of pregnant women shall be made mandatory in due course of time to enable the children born to HIV positive women live free from HIV infection.
- More thrust shall be given for sensitizing adolescent girls for preventing HIV infection by adopting appropriate awareness building strategies and developing sensitization modules.

- Emphasis shall be given to enhance the knowledge levels, skills and the presentation capability of NGOs to enable them to make an impact in the National and International conferences.
- Research studies shall be undertaken to study the impact of various drugs and to assess the long term effects of drug resistance.
- More number of voluntary Counselling and Testing Centres shall be created and a system shall be evolved to ensure better counselling of the individuals.
- Research shall be encouraged to study homosexual practices among students and to evolve intervention programmes to tackle the problem.
- Involvements of religious leaders, opinion leaders in the community and the community as a whole shall be mobilised to strengthen the prevention efforts and to enhance the Societal role.
- The high risk groups shall be identified and appropriate targetted intervention programmes shall be evolved to reach them for positive behavioural change. Migrant labourers and men having sex with men shall be included in the intervention efforts.
- Appropriate culture specific intervention programmes shall be developed to reach the affected and unaffected population and to bring about attitudinal changes, among them.
- HIV/AIDS programme shall be integrated into other Health related programmes to make the programme sustainable; The effective models for home based care shall be evolved and implemented. The multi sectoral approach shall be initiated and the Police Force shall be sensitized on the epidemic to extend support to NGOs in reaching the high risk groups.
- Management of private medical institutions and private medical practitioners shall be sensitized to avoid denial of treatment services to the HIV/AIDS affected. Relevant training programmes shall be developed to train all concerned to handle the affected.
- Industrialists and business houses shall be involved in HIV and AIDS programmes to further strengthen the initiatives aimed at creating awareness and strengthening the Health care delivery system. The funding agencies shall be sensitized on the culture, region-specific programmes and also on the emerging issues.

THE VIEWS & THOUGHTS...

The participants shared their experiences learned at the conference and expressed their concern with regard to the need for intervention in specific areas in Tamil Nadu. The points are summarised below:

Dr. Suniti Solomon, YRG Care, Chennai, reported that where informed consent was concerned, unlike other countries the patients in India either did not understand or like signing for this. She learnt that there were incentives given for breast feeding in some countries and the ethics of this needed to be examined. According to her, in Canada for instance, testing for HIV was mandatory among HIV positive women, and there was no reason as to why India should feel "bad' about this. She reported that medication through free Nevropine was covering only 10% of the developing countries needs. She raised the question as to who bears the balance 90% of the cost.

Dr. Deivanayagam, Superintendent, Govt. Hospital for Thoracic medicine, Tambaram, Chennai, reported that the conference was very interesting. He stated that Uganda had a people's movement to tackle HIV/AIDS and there was need for such a movement in India. According to him, it was important to include the participation of opinion makers such as lawyers, religious leaders etc. from the community in the HIV/AIDS intervention programmes. He added that the message of sexual abstinence to prevent HIV/AIDS needed to be explored.

Mr. G. Pramod Kumar, Special Correspondent, "The Hindu", Chennai, said that it was a pity that very few newspapers covered the event from India unlike Latin American countries for instance. According to him, one of the main issues at the Conference was unaffordability of medication. He reported that it was heartening and impressive to note a high visibility of positive people who attended the conference from both India and other countries. He added that there was need for more programmes in schools/colleges; and that the cooperation and inclusion of the police force for the programmes was important.

Mr. Ganesh, YRG Care, Chennai, reported that there was a need for specific awareness programmes on HIV/AIDS prevention among adolescents in Tamil Nadu. According to him, the Conference had conveyed the message that this group was vulnerable and the future of this group needed to be addressed.

Mr. Hariharan, ICWO, Chennai felt that there was a need for more presentations through posters and research papers by NGOs from India. According to him, the quality of the presentations was poor, especially the posters. He proposed training programmes for NGOs in this regard.

Mr. Stanley Moses, ACCEPT, Chennai, said that the organising level of the AIDS Conference was very impressive. He proposed that India in future should host a similar Conference. He stated that there was a balance in the programmes between the scientific groups and community sessions. He added that unlike in the West where mother to child transmission had come down, India had

much to achieve in this regard. He felt that there was need for more interventions for men having sex with men as there were a large number of gay people in Tamil Nadu.

Ms. Celina D'Souza, Indian Network of People Living with HIV/AIDS, Chennai, reported that there were many debates and discussions at the Conference on the sexual and reproductive rights of positive women, and the rights of pregnant women. She stated that there were meetings amongst positive women too. Though the issue of consent was discussed extensively at the Conference, she felt that the HIV/AIDS infected just giving consent was not enough. It was important for the concerned persons to understand the implications of it and the responsibility was with the Treatment centre.

Mr. Sivan, AIDS Prevention and Control Project, Chennai, observed that the various presentations made by the NGOs from India was not up to the mark. Posters, oral presentations and research abstracts needed further refinement. He stated that there was a need for the NGOs to be trained and imparted skills in this area. According to him, there was a demand for publications by APAC at the Conference. He commended the news coverage by Mr. Pramod Kumar of 'The Hindu' newspaper on the Conference.

Ms. Kausalya of Positive Women Network, reported that she was able to share with other delegates about the self-help group for positive people in Tamil Nadu. According to her, there was a lot of curiosity to know the culture and religious practices in India by participants from other countries. She reported that during the Conference she was able to visit a family that was affected by AIDS. Ms. Julie, of the same NGO, added that it was said that it was still difficult to disclose the identity or the HIV status of persons in the Indian condition due to social stigma.

Ms. Rita James of Teddy Trust, Madurai, stated that the poster presentations were informative. She recommended that there was a need for the children of sex workers to be addressed and that there were very few organisations that offered services for this group. Boarding schools, daycare centres etc. needed to be set up. She learnt about the effective use of hand puppets for communication of information to the community. Ms. Amanda, Teddy Trust, reported that such Conferences enabled all those working in the field to share their energies and increased their motivation. According to her, there was a need to involve more business houses to participate in the HIV/AIDS issue and a global council for this was recommended by her. She stated that these business houses could sponsor a part of the programmes and should be able to include it in their agenda.

Ms. Anandhi Yuvaraj of positive women network, Erode, reported that she was able to help to conduct a small research study through interviews, on feedback about the Survival kit for Positive Women. She felt that such a kit would be useful in Indian settings. According to her, the multi-lingual nature of India would need careful translation if it were to reach all communities. Words like "lesbian' for instance, still needed proper translation in Tamil. She reported that rape was a social problem and was extensively addressed through role plays in South Africa. She added that it was impressive that condoms were made available at the University of Natal's gate.

Ms. Lalitha Kumaramangalam, Prakriti, Chennai, stated that it was sad that there was less representation by participants from Asian countries and women in particular. She stated that there could have been more discussions at the Conference on how HIV/AIDS can be prevented

among heterosexual men. According to her, the debate of gay movement vis a vis men having sex with men in India was more a political issue and she stated that the behavioural issues needed to be addressed. She suggested the linking up of positive peoples' groups and people/ NGOs working on HIV/AIDS to work together as they tended to drift apart. She added that it was heartening to see two Ministers from the Indian government were present at the conference and such political will was necessary. She recommended networking with other NGOs to care for the orphaned children of AIDS infected individuals and linking HIV/AIDS with other health programmes in Tamil Nadu. She added that Industrial houses, the Rotary etc. were showing keen interest in HIV/AIDS.

Dr. Pratap Thariyan, Professor and the Head of the Department of Psychiatry, CMC, Vellore, said that India needed to lobby more for the availability of free medication for the HIV/AIDS infected persons. The long-term effects of drug resistance also needed to be studied according to him. He recommended setting up Voluntary Testing Centres in Tamil Nadu through a planned strategy. He stated that trained counsellors were yet to actually work with infected individuals. Such centres would be able to provide the counselling service at prevention and treatment intervention levels. Topics such as nutrition and general health care were to be included. The role of APAC, Chennai in setting up such centres along the highway was suggested by him.

Dr. Ganapathy, Madras Medical College, Chennai, stated that the Community Indaba programme organised at the conference was impressive. He stated that through syndromic management, Africa was able to effectively control STD cases. He suggested that there was a need for mass treatment packages to reach the high risk groups. He reported that there was much advocacy of female condoms in Africa. According to him, there was a study in Chennai that indicated that 35% of students had homosexual contacts, and there was a need for intervention for this group. He also stated that there was a need to start programmes for very young children being the future generation.

Ms. Dora, USAID, New Delhi, observed that a long term approach to all interventions was a lesson she learnt from the Conference; and 'Care' was now an integral part of all prevention programmes. She felt that there could have been more discussions on opportunistic infections. She reported that there was a need to involve the policy makers and NGOs for a more effective intervention.

Dr. Kumarasamy, YRG Care, Chennai, reported that the conference was useful and that there was a need for more participation from the medical community in India. According to him, there was not much new data on vaccines developed for HIV/AIDS and trials were still underway. He reported on learning that there was resistance to Nevropine among pregnant mothers. He added that there was a need for scientific data on Sidha treatment trials for HIV/AIDS.

Ms. Lakshmi Sankaran, VHS-APAC, Chennai, stated that during her field visits in Tamil Nadu, she observed that the patients preferred treatment from private doctors, physicians from distant towns or quacks compared to STD clinics in government hospitals. Factors such as non-availability of the doctor/medical staff at the outpatient unit, lack of confidentiality, stigmatising attitudes etc. were some of the reasons reported by the patients. According to her, some of these doctors had already received training in the syndromic approach for treating STDs. **Dr. Bimal Charles,** Project Director, APAC, Chennai, recommended that there was a need for the community to be involved in the programmes and not just as a token involvement. He stated that with government support, there could be more effective programmes in Tamil Nadu linking Prevention, Care and Testing facilities under one roof. He added that the attitudinal change among the Doctors in Government service was important to enable in providing non-stigmatised approach for the treatment of the patients. New target groups such as men having sex with men, migrant labourers for instance were to be developed. He recommended setting up of feasible home based models for the HIV/AIDS infected persons.

Dr. K. Gopal, IAS, Project Director, TNSACS, Chennai, reported that the Conference enabled him to learn about the success stories in Uganda. He reported that AIDS is a crisis of governance and not just a health problem. He reported that India could end up in a catestrophe like Africa if the problem is ignored and that there was need for more targeted interventions. He called for the need for coordination among various groups besides high risk groups. He added that as it cost the patient at least Rs 3,500/- per month for anti-retroviral therapy, there was a need to explore other alternative therapies. He recommended that a Directory of services for HIV/AIDS be compiled and publicised. He requested the participation of all NGOs by providing information for the benefit of both positive people and the general public. He has requested all the stakeholders to share the information, experience, success stories to evolve a strategy to combat the HIV/AIDS.

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