A Brief Report on

National Consultation on Access to Treatment for People Living with HIV/AIDS (PLWHA)

26th February 2009

India Habitat Centre, New Delhi

The National Consultation on Access to Treatment of HIV/AIDS was held on 26th Feb 2009 at India Habitat Centre, New Delhi. About 40 people from various organizations across India participated in the consultation (list of participants attached). The consultation was jointly organized by CENTAD, New Delhi and Prayas, Chittorgarh.

The objectives of the consultation were:

- To develop greater trust between different stakeholders and strengthen efforts made by different stakeholders in the country on access to treatment of HIV/AIDS through sharing evidence-based feedback.
- Identifying key roadblocks in implementing programs for access to treatment of HIV/AIDS and possibilities of different stakeholders in addressing them.
- Fine-tuning implementation steps and strategies for fulfilling gaps in the policies and programs.
- Identifying key issues for future planning processes.

The consultation had participation by people from various field of works significantly concerned in one or the other way with the access to treatment issue in general and treatment of HIV/AIDS in particular. The consultation constituted of participatory brainstorming sessions, supported by panel discussions on identified specific topics relevant to the issue of access to treatment.

The participants belonging to various fields such as civil society organizations, government officials, SACS, PLWHAs, lawyers, doctors, students, social activists, research institutes, human rights networks etc marked their presence in the consultation.

Session I- Introductory Session:

The consultation started with a welcome note by Chhaya Pachauli from Prayas which was followed by a round of introduction of the participants.

Dr. Narendra Gupta, Secretary Prayas then gave a brief introduction of the consultation and informed the participants about its chief objectives. He said that though the consultation majorly focused on HIV/AIDS, it also applied to the treatment access in general for any other ailment. He also said that access to treatment of HIV/AIDS was a

rarely talked issue and seeks more focus from people from different fields of work and especially those involved with issues of health and medicines.

This was followed by key note address from Dr. Amit Sengupta. Dr. Amit Sengupta deliberated on the issue of Access to Treatment in general unspecific to HIV/AIDS. He said that worldwide there are about 2 billion people who lack access to essential medicines. Improving access to existing medicines could save 10 million lives each year. He also said that access to Medicines needs to be seen as a component of the broader issue of Right to Health and that locating Access to Medicines in a Rights Framework requires that obligations are identified for different actors who have a major role in modifying access. He stressed on obligations from states (country govts.), pharmaceutical companies as well as the medical professionals. He went ahead to explain how price acts as the single largest barrier to access. He also spoke on issues of monopoly in drug production, sales and distribution. Speaking on equity in availability of medicines, Dr. Amit Sengupta said that it is necessary that the medicines are distributed such that they preferentially reach the underserved. He said that health systems need to be designed to promote equity in distribution, but actually many Health Systems following the institution based model do the opposite.

Talking on quality of medicines, Dr. Sen Gupta explained how sub-standard quality, translates into poor access and poorer populations are likely to be exposed to a much larger volume of such drugs. He further pointed out that a study in India showed that over half of medicines prescribed are either irrational or hazardous or both. He said that ideally medicines in an Essential Drug List (EDL) should address 95% of needs, however in practice this seldom happens, even in public institutions. Speaking on research and development he said that there is an urgent need that alternate models for R&D with public ownership over the final product are promoted. He also explained how clinical trials in developing countries are much more prone to the flouting of promotional norms.

Session II- Situation Analysis (Panel Discussion)
In Chair: Dr. S. Srinivasan, LOCOST

SPEAKER 1: Mr. K. M. Gopakumar, Third World Network
TOPIC: Access to treatment and Equity

Mr. K.M. Gopakumar regarded equity as one of the major issues that need to be highlighted when it comes to access to treatment. He in his deliberation emphasized on different facets of equity in terms of cost of treatment (affordability), availability of services, government policies and gender issues. He said that Current treatment costs, even if subsidized, make treatment unaffordable to many, and may result in the serious risk of treatment interruptions for those who can afford treatment only intermittently. This makes access to treatment a difficult task for people who survive in poor and resource deprived settings.

He also focused on gender issues especially that of marginalized groups such as MSMs who due to already prevailing stigma and taboos attached to them prefer to stay away from treatment and are most deprived of care and support.

SPEAKER 2: Ms. Rachel Stephens, Human Rights Law Network
TOPIC: Treatment and Rights: Gender Perspective

Ms. Rachel began her deliberation by stressing on the fact that how access to treatment issue should necessarily be treated as a human rights issue. She said that right to quality health care services is just another facet of right to life. She mentioned that as rights guaranteed under the Constitution of India are universal – irrespective of gender, race, nationality, age, caste, religion, economic background etc, the same holds true for the treatment of HIV/AIDS as well.

She further stressed that women are increasingly vulnerable to HIV/AIDS. She supported her arguments with facts and figures such as global prevalence among women has accelerated from 41% of infected adults in 1997 to 50% in 2008 (UNAIDS, Global Facts and Figures, 2008) and that in India, data from STD clinics show increasing representation of young women (i.e. below 30 years old) being HIV positive. She said that in India the rates of HIV infection amongst women are increasingly rising. Many believe that among women, only sex workers are at risk, but HIV is increasingly affecting married women in monogamous relationships because their husbands are engaging in high-risk sexual activity outside the marriage. She also pointed out that most married women have little knowledge of the risks they face because, until recently, HIV/AIDS education and prevention programmes had been targeted only at "high-risk" groups such as truck drivers, sex workers and MSM groups. She regarded women physiology, early marriage, low self perception of risk, lack of access to health services, unequal gender norms and the fact that women are expected to play the role of carer as the major factors for increasing vulnerability of women towards HIV/AIDS in India.

She further talked on Access to treatment issue in context of men who have sex with men (MSM). She spoke about how Section 377 IPC, criminalises sex between same sex partners, and how society's discrimination force MSM underground – difficult to reach out and help them access treatment. She also said that disclosure of HIV status for MSM is a double disclosure as it also entails disclosure of sexual orientation, and thus discrimination as a result of both.

SPEAKER 3: Ms. Leena Menghaney, Lawyer/ Medesines Sans Frontiers (MSF)
TOPIC: Expanding AIDS Treatment: Dilemmas of Unequal Access in India

Ms. Leena Menghaney began with rewinding the roll out of ARV by GOI in 2004. She said that though the start was slow, but at present Nearly 200,000 thousand people living with HIV are accessing from 197 ART centres across the country - doctors, diagnostics, counselling and essential medicines that treat opportunistic infections and those that fight HIV itself, known as anti−retroviral drugs. She further talked about the major challenges that stand in front of us with regard to treatment of HIV/AIDS. She pointed out that India's programme is going to face the challenge of drug resistance – something that other AIDS treatment programmes of Brazil, Thailand and South Africa have faced.

She stressed on availability of 2nd line treatment as the majority of people living with HIV on the government ART programme will inevitably over the years develop resistance to their first combination of ARVs. Some already have. Therefore the need for access to newer combinations of antiretrovirals will become increasingly acute, as patients need to switch to regimens that are effective. She also criticised the criterion for accessing treatment. She informed that priority is being given to women and children living with HIV which restricts those who most need the treatment. Patients who were unable to wait for 2nd line ARV treatment due to their deteriorating condition and were being treated in the private sector will not be allowed to now switch to the government programme unless their economic status is 'below poverty line'. She also mentioned that others who were failing first line but have been under treatment for less than two years in government ART centres too are ineligible. She said that this will only drive PLHAs to the unregulated private sector where irrational drug regimens are common.

Speaking on pediatric treatment, Ms. Menghaney said that pediatric studies and formulations are not a priority for MNCs who derive their profit from developed country markets. Majority of ARVs approved by the U.S. FDA are not approved for use in children and do not come in any kind of paediatric formulations. She also explained how registration issues have delayed scaling up of infant diagnosis under the national programme. Further deliberating on PPTCT she told that for women who do avail PPTCT services, the current PPTCT guidelines offer single-dose nevirapine (sd-NVP) for women and infants, a standard of care that results in troubling transmission rates but also associated with the development of NVP resistance which later complicates ARV treatment for the woman.

Session III- Experience Sharing
In Chair: Mr. Achyut Das, AGRAGAMEE, Kashipur (Orissa)

The session had some positive people as speakers who shared personal instances of discrimination and denial of health care services. The speakers were from Rajasthan, Gujarat and Chhatisgarh. Apart from that two speakers presented on initiatives taken by their respective organization while working on HIV/AIDS and treatment.

SPEAKER 1: Dr. Shrinivas Darak. Prayas Pune

Dr. Shrinivas Darak informed that Prayas is an NGO working since 1994. The health group of the organization works on Clinical and counseling care to PLHA (both adults and children), laboratory facilities for monitoring HIV disease, training, intervention programs, preparation of educational material and research. He further informed that PRAYAS Amrita clinic has provided care to approximately 4500 HIV infected patients since 1989. He said that in order to ensure treatment to people it also becomes necessary to ensure availability of medicines, quality of care, work against stigma and discrimination and care of the affected family members.

He then talked about organization's work for pediatric HIV care. He told that PRAYAS Amrita clinic provided care to approximately 400 HIV infected children. The organization serves a library, recreational activities and separate OPD for children on Tuesdays and Fridays in the afternoon for pedatric care. Speaking on challenges in accessing care Dr. Shrinivas stressed on unavailability of services, especially in rural areas, denial of obstetric care in private sector and stigmatization and discrimination by health care providers. He then suggested that the following improvements are the call of the hour:

- Quality of services in public facilities should be improved
- Meaningful public private partnerships should be established
- AZT based regimens should be given in the national PPTCT program
- Pedantic care should be scaled up in public and private health care facilities

SPEAKER 2: Dr. Anand Sivaraman, ReaMetrix India Pvt Ltd, Bangalore

Dr. Anand Sivaraman presented the work of his organization on Innovative, Multi-platform, Affordable CD4+ enumeration reagents that need no cold chain, impacting HIV/AIDS management in resource poor settings. He mentioned the following current issues with CD4 testing in resource poor settings:

- High cost of testing
- Poorly developed cold chain in the transportation, storage & use of reagents
- Aging of blood samples that are transported to centralized testing facilities
- Complicated assay workflow with multiple critical pipetting steps leading to errors in CD4 count enumeration

He said in order to counteract the problems, ReaMetrix innovated the following approach:

- Undertook a study of the anatomy of cost of CD4 testing
- Worked on a locally relevant innovative product delivery model – dried reagents
- Re-designed reagents to enable staining in collection centres
- Simplified assay workflow with a single critical pipetting step – reduced chance of human error

He said that in India, the real challenge lies in transporting blood samples from remote areas to centralized testing centers. Often times, this leads to "aged" blood samples (> 48

hrs), making it unusable. Blood collection centers need access to cold-chain to enable storage of liquid reagents, if they were to stain samples and then ship them. However, dried reagents can be stored and transported at room temperature. Blood can be collected, stained and fixed at the point of collection before being shipped to a central testing facility at room temperature. The stained samples can be stored for up to 7 days at room temperate without any statistical difference in CD4/CD8 counts on 1st day vs. the 7th day. He further informed that dried Reagents are stable at room temperature for more than 12 months and that use of dried reagents in resource poor settings without cold chain/ refrigeration enables increased penetration into remote areas**.** Commenting on the advantages of ReaMetrix Reagents Dr. Anand put up the following points:

- All reagents already formulated, unitized and dried
- Steps as simple as mix & read
- No cold chain in transportation or storage
- Long shelf life and reduced waste
- Less opportunity for pipetting errors – with fixed volume pipettes, sample processing is made very easy
- All this without compromising quality or affordability.

Session IV- Meeting the Challenges (Panel Discussion)
In Chair:Dr. Mira Shiva, Initiative for Health, Equity and Society

SPEAKER 1: Dr. Gopal Dabade, All India Drug Action Network
TOPIC: Health System and Service Delivery

Beginning with the deliberation Dr. Gopal Dabade said that India seems to have been plagued with several public health problems. Within the current situation India has the double burden of both the infectious and the non-infectious diseases – both on the increase. He regarded HIV/AIDS as add on to these problems, which has attained significant attention all over the world. He pointed out that one of the major hurdles in the field of HIV/AIDS is the lack of authentic and definite facts and figures, so it is almost like sailing (or sinking) in unknown waters.

Dr. Dabade then went ahead to share few of his experiences working with people on HIV/AIDS and described some of the learning out of them. He said that a dominating and unregulated private medical sector is the big hurdle for proper health delivery. He said that the problem is further aggravated by inequality that has been created by the onslaught of globalisation. He pointed out that 26 districts which have been identified by NACO as high prevalence districts mostly belong to the states of Madhya Pradesh, Uttar Pradesh, West Bengal, Orissa, Rajasthan and Bihar. These are also the BIMARU states which suggest that they have a weak public health system and general health care delivery system. Referring to Alma Ata Declaration Dr. Dabade said that 30 years later old challenges remain and new priorities have emerged. Missed targets have been postponed to 2015, but again, Millennium Development Goals risk not be met. Just as thirty years ago, the major obstacles lay in lack of vision and political will, and not in

lack of resources. He concluded by saying that in the spirit of Alma Ata, a systemic approach to health is needed, one promoting human rights and social justice, rather that, once again, one selectively focused on improbable quick-fix solutions for single diseases.

SPEAKER 2: Dr. Jagdish Chandra, Professor of Paediatrics, Lady Harding Medical College
TOPIC: Pediatric Treatment (Managing HIV infection in Children)

Speaking on HIV infection management amongst children Dr. Jagdish Chandra said that management deals with three issues; Supportive treatment, ART and prevention. He told that mother to child transmission (MTCT) is the most common mode of acquiring HIV in children. MTCT rates vary from12 to 54% worldwide and in India MTCT rate is 30%. He also informed that while breast feeding increases the risk of MTCT, elective caesarean can decreases the risk. He said ART to mother can also reduce the risk of transmission to some extent.

He then focused on the issue of breast feeding which has a major role to play in transmission of infection amongst children. He said that though in developed countries it is recommended that breastfeeding be avoided by all positive mothers, the recommendation does not hold good in countries like India especially in poor settings. He then brought into light the WHO recommendation which says that as advantages of breastfeeding far outweigh the increased risk of HIV transmission through breastfeeding, hence HIV +ve women in resource constraint countries should continue breastfeeding their infants. Coming to supportive care, he focused on issues of infant feeding, nutrition, immunization, prophylaxis against infections and psycho-social support. He said that early identification of HIV infection in children can substantially help. One then needs to be guided on infant feeding choices, decisions regarding cotri. prophylaxis and ART, differentiate other diseases occurring in non-infected children as well and to alleviate "stress of unknown" and planning to deal with HIV status. Speaking on psycho social support, Dr. Chandra stressed that one has to be true and hopeful, provide support, confidentiality and shelter/ Foster placement. He said that amongst adolescents it becomes necessary to prevention risky sexual behavior and habits of drugs and alcohol.

SPEAKER 3: Dr. L. Ramakrishnan, SAATHI
TOPIC: Treatment Literacy

Dr. Ramakrishnan began with explaining how treatment education can lead to treatment preparedness. He informed that a patient can be considered treatment literate when he or she:

- knows the medicine's name
- knows how and why the medicine is effective
- knows where in the body the medicine works
- is aware of side effects and how to manage those side effects
- is able to self-monitor medication consumption
- is aware of proper nutrition while on medication

He stressed on treatment literacy on the following subjects:

- Opportunistic Infections (including TB) prevention and management, including home management and when to see the provider
- ART adherence and side-effects
- STI screening and treatment, including HPV, Hep-C, and partner treatment
- Post-exposure prophylaxis
- Surgery and hormone therapy for transexual sexual reassignment surgery, including hormones X ART interactions
- Nutrition and Exercise
- Change in behaviors and practices to reduce horizontal and vertical transmission risk
- Reducing myths and misconceptions around transmission, treatment and (lack of) cure

Dr. Ramakrishnan further spoke on the current needs in patient literacy. He said that educational/awareness materials need to be standardized and age-appropriate. They also need to be translated in as many languages as possible so that most people can benefit from them. He also focused on training and mentoring healthcare workers in imparting treatment literacy. He said that there is also a lack of educational material with MSM, Transgender and IDU-specific contents. He stressed on the urgent need to scale up community preparedness and inclusion of treatment literacy component at every counseling/ health-education opportunity.

SPEAKER 4: Mr. Vijay Nair, Udaan, Mumbai
TOPIC: Treatment and Support for Marginalized Groups

Mr. Vijay Nair said that the attitudes of PLWHA are changing and they are developing positive outlook towards life, becoming more optimistic and wanting to live. However he said that when it comes to treatment and care for marginalized groups, there is still a long way to go. He emphasized on the issue of men who have sex with men (MSM), which is not usually discussed in public because of sexual and societal taboos. He insisted that the issue of HIV/AIDS infection among this group must be addressed in an expedient and efficient manner. Equitable health care should provide for all human beings, regardless of sexual orientation. The needs of marginalized groups must be incorporated into preventive and curative treatment plans, education programs, and other interventions.

Concluding Session:

Mr. Santhosh from CENTAD summarized the day long discussions and deliberations and extended vote of thanks to the participants on behalf of the organizers.

List of Participants

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