Rights Based Approach in HIV/AIDS

The HIV experience has shown us that to prevent the transmission of HIV it is necessary to empower those infected and affected, not only individuals but also the communities, particularly the ones who are traditionally marginalized such as sex workers, Men having Sex with Men and Injecting Drug Users. On the other hand if one denies the rights to those people it is likely to drive the disease underground and thereby facilitate the transmission of HIV.
Infusion of rights in prevention science -- SONAGACHI

**Intervention**

- STD/HIV/AIDS project introduced in 1992
- Components: STD treatment, IEC & Condom promotion
- Strategies: *Participatory, Peer oriented & Rights based*

**Impact**

- **Condom use**: Up from 3% in 1992 to 90% in 1998
- **STD rates**: Fell from 25.4% in 1992 to 11.5% in 1998
- **HIV prevalence**: Has remained stagnant at 5%
Mumbai experience

in Mumbai, India the rate of HIV infection amongst sex workers is 55-75%

the increase of HIV infection amongst sex workers has been increasing exponentially
Sex Workers

Infection among CSW’s in Mumbai has increased from 1% - 51% in 5 years

( According to NACO Report 97-98)
Sonagachi: lessons learnt

• The accumulated strength derived from collectivization has enabled sex workers to break the silence and stand up for their rights including protection against HIV/AIDS.

• The Sonagachi intervention through basic humane approach and non-use of coercive tactics, has enabled sex workers to address the roots of vulnerability.

• It has been recognised internationally for demonstrating the successes of a rights based interventions among one of the most marginalised populations.
Success of Rights based approach in HIV/AIDS

- a study published in *The Lancet* in 2006, showed reduction of HIV-1 prevalence in South India, and cited amongst other things increased condom use by sex workers as a contributing factor.

- a study presented at the *International AIDS Conference in 2004*, has shown that the rapid increase in condom use that occurred within the intervention community has been sustained over time, contributing to low HIV prevalence among sex workers.
Public Health Models: ISOLATIONIST v. INTEGRATIONIST

**isolationist**
- mandatory testing
- confidentiality breached
- discrimination if HIV-positive
- ...leading to isolation of HIV-positive person...

**integrationist**
- voluntary testing
- confidentiality maintained
- no discrimination if HIV-positive
- ...leading to integration of HIV-positive person...
Rights based approach - Consent

• Common law countries unanimously recognize the paramount importance of consent, or the right to self-determination or autonomy.

US Supreme Court judge, Justice Cardozo, :

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation on his patient without his patient’s consent commits an assault, for which he is liable in damages.”
Rights based approach - Consent

- The right to autonomy and self-determination has also been adopted in international humanitarian law in various instruments such as the UN Charter, UDHR, ICCPR and other international instruments such as the Declaration of Helsinki adopted by the World Medical Association in 1964 as a statement of principles for medical care and research. These principles respect for the individual, the right to self-determination and the right to make informed decisions.
CONSENT

DOCTOR - PATIENT RELATIONSHIP

• relationship between unequals:
  Doctors have *better knowledge
  *larger experience
  *Trust

• Therefore the duty of the physician:
  *is to provide honest information to equalise the relationship

• BASIS OF THE DOCTRINE OF INFORMED CONSENT
Counselling and treatment literacy

The HIV experience has shown that it is not only the formal legal elements of consent, benefits, risks and alternatives that are important but also how that information is delivered. This is particularly true in ailments, which require long-term treatment and adherence to the treatment protocols and drug regime.

In the HIV scenario, counselling and treatment literacy have played a significant role in:

- Making the PLHAs fully informed; and
- Thereby, enabling them to participate actively in their own treatment.

The ARV Rollout study by LC shows that adherence to ART was significantly more in centres where treatment and adherence counselling was imparted to PLHAs on every visit to the centre.
Counselling and treatment literacy

• A study in China demonstrates the consequences of absence of treatment literacy. Drugs were distributed, without attempts to explain how they work and their side effects. Almost 90% of people in one village simply stopped taking their ARV drugs within a short time. When some people began to experience side effects, others became fearful and stopped taking them. There was no treatment literacy, so rumours began, and misinformation spread quickly.

• A study in Tanzania found that non-adherence was associated with poor knowledge, the absence of information, lack of treatment guidelines, and a negative perception of treatment.
Treatment literacy programmes

- TAC, South Africa – involvement of PLHAs in developing literacy material is integral to program success.
- Pilot projects in South Africa show that high levels of adherence to ART emerge from a, "new relationship between HCW and patients." By using an empowerment framework, responsibility for adherence is given to, and instilled in, the patient.
- Coetzee & Schneider – this approach differs from the “traditional paternalistic & passive relationship b/w HCW & patients,” and activates agencies within patients to take control of their own treatment.
Treatment literacy programmes

• In India, PLHAs and NGOs have insisted on treatment literacy as a tool to ensure adherence and delay resistance, which has been accepted by NACO. NACO will be including that in its program formally.

• Whether experiences in HIV have any bearing on TB programmes, at a time when:
  - TB is emerging among PLHAs
  - MDR & XDR is emerging among TB patients.

• Though these cannot be regarded as a failure of the TB programs studies show that this could be due to the adoption of medical intervention model.
HIV & TB Intervention Models

- **HIV program** – empowerment model – which allows PLHAs to take *personal responsibility* for testing and treatment. This develops an internal locus of control.

- **DOTS program** – HCW or a family member closely supervises and monitors treatment. *Reliance on others*, diminishes patient's agency to adhere to treatment.

- Some critics of DOTS, inspired by Foucault, single out the “supervised swallowing” aspect of DOTS as “dehumanizing” and “authoritarian.”

- Is constant supervision an effective way to promote adherence?
Rights based approach and DOTS

• The DOTS program lacks a rights-based perspective; the agency of patients is ignored, and there is no emphasis on consent, counseling or treatment literacy.

• The traditional application of DOTS also ignores cultural and gender contexts and is often blindly applied without attention to the local context.

• A study of the evolution of XDR F15/LAM4/KAN strain of mycobacterium TB in South Africa, showed that many TB patients, due to an absence of susceptibility testing, were treated with inappropriate drug regimens, which contributed to the development of drug-resistant strains.

  - Manormoney Pillai and Willem Sturm, Strain of Mycobacterium tuberculosis in KwZulu-Natal, South Africa, Clinical Infections Diseases.
Rights based approach and DOTS

• Other studies have suggested that the strict universal application of DOTS can decrease effectiveness of TB control - Lienhardt C, Ogden J (2004) *Tuberculosis control in resource-poor countries: have we reached the limits of the universal paradigm?* Tropical Medicine & International Health 2004.

• On the other hand a study conducted in South Africa reported greater treatment success among patients who managed their own treatment compared to those who were under direct observation by a health worker. - Zwarenstein M, Schoeman JH, Vundule C, Lombard CJ, Tatley M: *Randomised controlled trial of self-supervised and directly observed treatment of tuberculosis.* Lancet 1998,
Rights based approach and DOTS


• A review by the WHO on empowerment of the TB positive persons, while being cautious, and citing innumerable examples of the success of empowerment to control TB, shows that
Rights based approach and DOTS

interventions that enable TB positive persons to take more responsibility for their health and in particular for adherence for treatment, organizing TB positive persons into groups, ensuring patient centred TB, and helping TB positive persons to use advocacy to improve TB control.


I hope that in the very near future strategies associated with successfully empowering HIV patients to adhere to treatment, will have a chance to be further developed and be refined in the treatment of TB. The dialogue between the communities in the two, HIV and TB, and health care workers and policy makers is a must.
Research & Development

• Historically, R&D has been based largely on the patent system. As a result, research for neglected diseases, including TB and Malaria, has been ignored.

• The Patent system has failed in delivering new drugs. Data from US FDA shows that in the period from 1995 to 2004 only about 300 NCEs were approved.

• Significantly the first line drugs to treat TB are those developed in the middle of the last century. The chances of having a new drug regimen (two drugs) for TB is not likely for another decade.
Research & Development

- On the other hand most of the drugs brought into the market are new forms of old substances. These may be therapeutically efficacious *only in a few cases*. Despite that the costs of the drugs has been high.

- The irony is that the drug industry has huge profits but the insignificant amounts for research for neglected diseases is not available. That is how the patent system has worked particularly in the US and Europe, leading to the debate about the efficacy of the patent system delivering new drugs.
Research & Development

- New Initiatives – Inter Governmental Working Group on Public Health, where new methods being proposed to reward innovation, such as prize funds, global funds etc.
- Urgent need is to de-link the price of the product from the costs of Research and Development.
- Community based interventions need to be supported –
  - AIDS community has lead the demand to institute changes in the funding for R & D.
  - IGWG has been set up pursuant to the report of the WHO Commission on Intellectual Property, Innovation and Public Health with pressure from activists working on medicines, particularly HIV.
Threat to affordability, accessibility & availability of medicines

- Patent Act, 1970 provided for process patent Only, which the Industry could overcome more Easily. As a result:
  - India had a robust generic pharma Cos.
  - There was competition which kept prices low.
- Indian Generic Cos. Can produce the cheapest drugs in the world and supply 50% of the developing countries market.
- With the change in the Patent Law that source of cheap drugs may dry up and the patent system internationally will be put to the test.
Threat to affordability, accessibility & availability of medicines

• In 2005, Indian Patent Act was amended to provide for product patent, thereby becoming TRIPS compliant.

• Sec. 3(d) – does not allow patenting of new forms unless it is more efficacious than the known form.

• Sec 3(d) was challenged by Novartis in Chennai High Court. Fortunately the court upheld the constitutionality of 3(d).
Threat to affordability, accessibility & availability of medicines

• Barrage of criticism against Sec 3(d).
• Pressure from US drug manufacturers & USTR to introduce TRIPS plus provisions in the Patents Act, which will hamper availability, affordability and accessibility of medicines and drugs.
• Cost of 1st line ARVs was USD 10,000 per patent p.a. Cipla offered it at USD 400.
• The developing world is anxious whether generic Cos. In India will be able to deliver drugs at similar reduced prices?