

## CIVIL SOCIETY PERSPECTIVE OF TB CARE AND CONTROL IN INDIA: CHALLENGES & SOLUTIONS

### BACKGROUND:

#### RNTCP:

Over the years, India has made great strides in improving access to Tuberculosis detection and treatment across the country. India's Revised National Tuberculosis Control Programme (RNTCP), based on DOTS strategy is being implemented through the general health system of the states under the umbrella of National Rural Health mission (NRHM). The Programme is implementing all components of WHO Stop TB Strategy 2006 and has made great strides in achieving global targets for new smear positive case detection (NSP CDR) (70%) and treatment success (85%), as per the Millennium Development Goals (MDGs) and the related Stop TB Partnership's Global Plan (2006-2015).

The RNTCP has been one of the successful Public health Programs in India with a high detection and cure rate. Recently, the program has shifted focus to provide universal access for total TB care. In such a scenario of universal access, the non program service providers, both formal and informal become important stakeholders in the scheme of things. Effective involvement of these service providers would enable the program to go through the last mile in universal access.

#### CIVIL SOCIETY ENGAGEMENT:

**HISTORY OF CSO involvement:** TB Control in India started as a civil society initiative. In 1921, Dr. Lankaster working for the Government reported a high incidence of tuberculosis in India and recommended that the Government work closely with NGO's in controlling the disease<sup>1</sup>. India became a member of the International Union Against Tuberculosis (IUAT) in 1929, and in 1939, Dr Moller, Medical Superintendent of the TB Sanatorium in Madanapalli, AP, started the TB Association of India along with Dr B.K. Sikand<sup>2</sup>. Similar State TB association sprung up in a number of states in India and have always supported the TB control efforts of the Government. The recent efforts at supporting the Revised National TB Control Programme through civil society partnership are really a return to this spirit of cooperation. In 2007, World Vision facilitated the formation of the NGO TB consortium (NTC) and later in 2008; the Indian Coalition Against TB (ICAT) was pioneered by the Union, which was later expanded to a broader partnership through the leadership of IUATLD in India. The results of these collaborative efforts are the Partnership for TB Care and Control in India.

The "**Partnership for Tuberculosis Care and Control in India**" (**the Partnership**) brings together civil society across the country on a common platform to support and strengthen India's national TB care and control efforts. It seeks to harness the strengths and expertise of partners in various technical and implementation areas, and to empower affected communities, in TB care and control. The partnership consists of technical agencies, non-governmental organizations including coalitions for TB, community-based organizations, affected communities, the corporate sector, professional bodies, the media and academia.

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<sup>1</sup> [http://ntiindia.kar.nic.in/docs/nti\\_annals/pages/annalsthegenesis\\_22.htm](http://ntiindia.kar.nic.in/docs/nti_annals/pages/annalsthegenesis_22.htm) accessed on 25 October, 2010

<sup>2</sup> Prahalad Kumar, Journey of Tuberculosis Control in India, *Indian J Tuberc* 2005; 52:63-71

**The Partnership's Steering Committee** comprises members from various partner organizations, and standing invitees include the Deputy Director General (TB) of the Central TB Division (Government of India) and the Program Manager of the National TB Program (RNTCP), World Health Organization (India) representative and the Director, Union South East Asia Regional Office. Currently the Partnership includes 50 partners.

To help achieving the targets of universal access the Steering Committee members felt the need to look into the challenges faced by civil societies, identify them and suggest solutions to the challenges through their perspective. These recommendations could be added onto the RNTCP Phase 3 planning which is presently being undertaken by the National TB Program.

#### **PROBLEM STATEMENT:**

The problem of Tuberculosis in India: India still bears 21%<sup>3</sup> of the global burden of incident TB cases and has the highest estimated incidence of Multi Drug Resistant-TB cases (MDR-TB) (131,000 out of global incidence of about 500,000 in 2007. Extensively Drug Resistant TB (XDR-TB) has also been reported from India. HIV prevalence among TB patients is reported to be 4.85 %

The problem statement is further described under the following sections.

#### **1. SERVICE DELIVERY: RNTCP SERVICES:**

1.1: Basic DOTS: The RNTCP in India which has achieved a high detection rate and cure rate is shifting its focus on providing universal access to total TB care. With huge population and many hard to reach areas being geographically marginalised it becomes a colossal task to bring the services to the community which had been not reached so far. The task is made even more difficult in the absence of adequate manpower at the service delivery points.

We need to look at innovative ways to involve other service providers, both formal and non formal to reach the last bit to provide universal access.

1.2: HIV-TB: India being the highest TB burden country of the world is under the constant threat of rapid TB transmission to its 23 million estimated HIV infected population and accelerating their mortality. Detection of TB/HIV co-infected people is still a big challenge because of the inadequacies of cross referral between the TB and HIV services and absence of community based TB/HIV collaborative programs for the PLHIV. TB case detection in the HIV high risk groups is also challenging because of their marginalized status and poor access to TB services.

1.3: TB and migration: More than 90 million males (i.e., more than 25% of adult males) in India are migrants. About 51 million males migrate from rural areas, and nearly a quarter of them migrate from one state to another (Census of India 2001). This is likely to increase further (National Sample Survey 1992–1993; National Sample Survey Report No. 470, 2001; UNESCO 2002), due to growing economic disparities (Haberfeld et al. 1999; PRAXIS 2002; Srivastava 1998).

The migration pattern reveals the source mostly as socio-economically backward states like Bihar, UP, Jharkhand, Orissa, West Bengal, Madhya Pradesh, Chhattisgarh, NE states and destination as

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<sup>3</sup> WHO Geneva; WHO Report 2009: Global Tuberculosis Control; Surveillance, Planning and Financing

Gujarat, Maharashtra, Delhi, Punjab, and Haryana. Rural to urban migration is the most prominent feature.

Unhygienic and congested living conditions of the slums, lack of health facilities and policies especially in the unorganized job sectors, lack of proper nutrition, alcoholism and smoking, strenuous work for long hours and poor knowledge, misconceptions and negative attitude towards TB are critical factors that can lead to tuberculosis disease among the migrant workers. Studies also revealed that migration is one of the key reasons of drug defaulter in RNTCP.

1.4: MDR-TB: MDR TB (resistance to INH & Rifampicin) is estimated to be 3% in new smear positives and 12-17% among smear positive previously treated tuberculosis patients<sup>4</sup>. Given that India is home to 3.4 million tuberculosis-infected people with 1.9 million new cases added every year, even these relatively low proportions of resistance translates in to one of the largest human pools of MDR TB in the world<sup>5</sup>. More over as Dr. Chauhan points out that MDR TB patients often live for a number of years before they succumb and so maintains the chains of MDR TB, thereby threatening the success of the DOTs strategy. XDR TB, which is multi-drug resistances to INH, Rifampicin plus any of the Quinolones, is estimated to be 8% of all MDR TB cases. The implication of XDR TB is that even thought it may be a small proportion, the severely restricted treatment options makes it a dangerous problem. The introduction of the DOTs plus strategy under the RNTCP in August 2007 comes from the recognition that it is one of the major challenges to TB care and control in India.

## 2. ACSM:

The focus and objectives of RNTCP Phase II addressed “Information, Education and Communication” (IEC). There were three components to this, namely awareness raising, patient-provider communication and counseling. This was governed by 3 principles -1. IEC should be process rather than products oriented 2. Planning, choice of communication channels and monitoring should be decentralized. 3. Address social issues related to TB<sup>6</sup>

Currently, ACSM has now been adopted worldwide. **Advocacy** aims to secure needed financial resources and change policies, guidelines and procedures by influencing various stake-holders. **Communication** seeks to increase awareness, influence social norms, create behavioral change and improve interpersonal communication and counseling between people with TB, their families and providers. **Social mobilization** aims to change norms, improve and expand community services by bringing groups together to act at community level. ACSM activities are a means to an end and not an end in themselves, addressing key barriers to TB care and completing treatment and thus, support the achievement of RNTCP goals. Thus, in summary ACSM strategies need to meet four important TB Control challenges: 1) Mobilizing political commitment and resources for TB. 2) Improving case detection and treatment adherence. 3) Combating stigma .4) Empowering people affected by TB and their communities

## 3. PPM:

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<sup>4</sup>Consensus statement from the consultative meeting of national experts organized by the TB Research Centre, ICMR, Govt. of India, on 14-15 September 2007, at Chennai; accessed from [www.tbciindia.org/.../Consensus%20statement%20on%20MDR%20XDR%20TB%20-Final.pdf](http://www.tbciindia.org/.../Consensus%20statement%20on%20MDR%20XDR%20TB%20-Final.pdf)

<sup>5</sup> L.S. Chauhan, Drug resistant TB; RNTCP response, *Indian J Tuberc* 2008; 55:5-8

<sup>6</sup> Project Implementation Plan, RNTCP, Phase II 2005-2010, Central TB Division, MOH & FW, GOVT of India

With 70%<sup>7</sup> of health care in India being provided by the private sector, it is of great importance that this sector is effectively engaged and included in the treatment of Tuberculosis. Private health care is rapidly expanding in India. Data from the National sample survey shows that the public health sector has faced many hurdles in its outpatient services. Private providers are seen in India as the first point of contact for a majority of illnesses.

The private sector mentioned includes, allopathic, other systems of non allopathic medicine (Ayurveda, Hoemopathy, Siddha etc), traditional healers and pharmacists. Their involvement has been limited so far.

With large scale migration in India from rural to urban settings for economic reasons, it is the urban poor who access seek treatment for TB through private pharmacies and non –allopathic practitioners. With unregulated treatment practices, the MDR and XDR TB cases have emerged as a threat to successful TB treatment programs. These coupled with the stigma to HIV-TB cases (which make these patients seek treatment in the comfort and anonymity of these private sector providers) has made it ever so necessary to effectively include the preferred providers of the urban poor in the scheme of things for strengthening the TB program in India and improving coverage and utilization of services.

## **CHALLENGES:**

### **A. RNTCP SERVICES:**

#### **A.1: Basic DOTS**

- To reach certain population group with TB information and services i.e. hard to reach areas, natural disasters prone area, migratory population, HIV high risk groups, street dwellers, urban slums, tribal population etc.
- Incidence of inappropriate care and rejection of patients on the basis of their being ‘non-ideal’ candidate who will spoil the statistics hence people without permanent address and migrants may not be enrolled under DOTS despite them needing care<sup>8</sup>
- Deficiencies in supervision and meetings with community DOTS providers
- Stigma and discrimination still persisting preventing people from seeking early treatment
- Non compliance to regular treatment owing to various factors<sup>9</sup>
- Retrieval of defaulters still remains a major challenge
- Irregular payment of DOTS provider’s incentives
- Tracking of TB suspects’ referral is weak.

#### **NGO Schemes:**

- Insufficient knowledge of the NGOs schemes among NGOs and CBOs
- Delays in scheme approval and disbursement of funds

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7 National Commission of Macroeconomics and health Ministry of Health and Family Welfare. Financing and Delivery of Health cares services in India 2005.

<sup>8</sup> Ref: TB control poverty and vulnerability in Delhi, Tropical Medicine, International Health, 2002 /7:693-700 page no. Authors. V.Singh, A.Jaiswal, et.al.

<sup>9</sup> Lack of knowledge, stigma, inadequate staffing, frequent changes in staffing, traditional beliefs, negative influence of the powerful people in the community, etc.

- Currently available schemes are uniform across the country which make budgetary provision inadequate for difficult to reach geographical areas.

#### Lab Strengthening:

- Sputum transportation in hard to reach areas
- Inadequate number of functional<sup>10</sup> microscopic centres
- Information on contact tracing and INH prophylaxis services are inadequate

#### A.2: TB/HIV:

- low level of TB awareness and education in PLHIV networks
- lack of outreach activities for detection of suspected TB cases, due to the high vulnerability to TB among PLHIV
- coordination between the outreach activities of the two programs is grossly inadequate
- lack of involvement of existing HIV- TI ( Targeted intervention) implementing NGOs of NACP in the TB program resulting in low level TB case detection in HIV high risk groups
- providing HIV counselling and testing services to the TB patients and management of those TB cases who are co-infected by HIV

#### A.3: TB and Migration:

- No national level strategy and guideline for tuberculosis care and control for the migrants in India
- Large numbers of migrants are currently working in unorganized job sectors with no health facilities, insurance facilities and work place policy for disease care and control like TB, HIV including low level of awareness etc. Such workers are solely dependent on the relatively expensive private health sectors (including quacks and unqualified medical practitioners) for their healthcare.
- Treatment adherence is compromised due to frequent mobility and non reporting to the providers
- Women engaged in unorganized job sectors are particularly prone to tuberculosis due to continuous exploitation by the employers (lowest wage rates, lack of nutrition, strenuous work for non-fixed hours, and no policy for female workers).

#### A.4: MDR-TB:

- An important constraint in the DOTs plus strategy is the 5 month delay in the diagnosis of MDR TB and a further delay in putting these patients on the DOTs plus treatment protocol. In spite of the expansion of DST Laboratories under GFATM Round 9, insufficient laboratory capacity to carry out drug susceptibility testing (DST) for all new TB patients. However DST for even for treatment failures to 1<sup>st</sup> line drugs or patients being retreated is still inadequate. Unless DST facilities are brought closer to the point of care.
- The delay referral from peripheral health workers of patients suspected to have MDR TB is due to the poor understanding of MDR TB by these frontline workers.

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<sup>10</sup> Lack of staff ,lack of equipments ,reagents, etc

- Another reason is the alarming increase in HIV-TB a sub-population in which there is high prevalence of MDR TB.
- Unless DOTs is expanded rapidly to cover at least 80% or more of the patients (currently 60%) it provides the potential for MDR TB to grow.
- Inadequate attention to routine infection control measures both at the facility and at the household level provides the environment provides an environment that result in greater transmission and the more rapid emergence of secondary drug resistant strains.
- The size of the second-line drug market in India in 2006 at approximately USD\$8.4 million per year. The bulk of this is procured by the private medical sector. It is unknown how many patients have been treated using these drugs. No data exists regarding treatment practices in the private sector or medical colleges for patients with diagnosed or suspected drug-resistant tuberculosis.

#### **B. ACSM:**

- Political will varies from state to state and hampers successful implementation of TB care and control at the state, district, and local levels.
- There is a gap between the policies and the programme on the ground, even when good TB policies exist.
- lack of local ownership and buy-in of national TB programme
- Access to available IEC material is not adequate to the NGO partners for implementing TB programme.
- recognition and acceptance of local NGO partners into the programme hindered by no clear communication from the concerned authorities
- difficulty in coping up with the different NGOs with limited activities and budget
- comprehensive training programme to build capacity in ACSM planning, implementation, monitoring and evaluation
- Identifying ACSM strategies that consider local conditions like; political, social, cultural, economic etc.
- Conducting regular monitoring and evaluation of activities to provide feedback to plans and measure impact.
- lack of operational research to document good and innovative approaches that empower and involve patients and affected communities

#### **C. PPM:**

- Low uptake of the existing PPM schemes by private providers
- Trainings are not linked to the expected service delivery from the private providers
- Incorrect regimes for TB treatment by private providers<sup>11</sup>
- Over the counter prescription of TB treatment by pharmacist and unlicensed service providers

#### **RECOMMENDATIONS:**

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<sup>11</sup> Zarir FU, Lancelot MP et al. Tuberculosis management by Private Practitioners in Mumbai, India: Has anything changed in two decades. PLoS ONE 5(8): e12023. doi:10.1371/journal.pone.0012023

## I. RNTCP Service

### i.i: Basic Dots

- Strengthen the supervision of DOT's providers. There needs to be more regular training and on field supervision.
- Enhancing Case detection by evolving a more active case detection strategies including volunteers and existing DOT's provider and their networks and by introducing contact tracing.
- The need for counselling TB patients is critical to their completion of the course of treatment and so it recommended that councillors be included both at the TU but also at the field level.
- There is a need for more robust monitoring and to redresses problems both at the block and the district level. The involvement of NGO's and civil society in this has been limited. It is recommended that NGO's be involved in this.
- The creation of state level and eventually a national level electronic data base of TB patients.
- Involvement of NGO's by the District TB Societies especially in the planning and the design of the District TB plans.
- NGO schemes: The main issues faced by NGO have been difficulty with released of funds on a timely manner resulting in cash flow problems. Many of the smaller regional NGO's have tended to drop out. We suggest that clearer and more precise operational guidelines be developed for the NGO schemes

### i.ii: TB/HIV:

- Coordination with NACO and SACS to facilitate TB training of the TI implementing NGOs that can further improve TB case detection among HIV high risk groups
- Coordination with national, state and district level PLHIV networks for imparting TB training and education and enhancing their participation in the TB/HIV collaboration
- HIV training of the community DOTS providers to enhance HIV testing and counselling of their TB cases and providing necessary support to the TB cases who are co-infected by HIV
- Both community DOTS programs and home-based HIV care services should work together to improve drug adherence, providing TB education to PLHIV community and facilitate cross referrals. The long duration of treatment required for both TB and HIV make adherence a challenge, but community-based groups can help to overcome the barriers. Community-based TB-HIV collaboration is important for all cases, but it may be particularly important for drug users and other populations needing special consideration. For such populations, adherence to treatment is high if the right support services are available.

### i.iii: TB and migration:

- The ACSM program of RNTCP should work with the existing migrant workers' unions<sup>12</sup> in the urban set ups and sensitize them on TB, RNTCP and DOTS.

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<sup>12</sup> Porters' union, Rickshaw pullers' union, Truckers' union, Auto-drivers' union, House-maids' union, Factory workers' union, Vendors' union, Hawkers' union, Barbers' union etc

- The migrant workers should be mapped in the urban and peri-urban areas (construction sites, street dwellers, illegal residents along the railway tracts, brick kilns, sabji mandi etc.) and provided RNTCP services (like sensitization on TB, identification of suspected TB cases, referral and tracking) through community-based programs as part of the ACSM plan and activities.
- The TB component should be introduced into the existing HIV programs for migrant workers after collaboration with National AIDS Control Program.
- It is important to initiate advocacy and develop collaboration with Ministry of Labor for restoration of rights and entitlements of the poor migrant workers with special focus to women that can be also useful for communicable disease control and care like TB, HIV etc. The TB partnership members should do the important monitoring targeting especially the unorganized job sectors
- The ACSM program should provide support to the local level small and medium factories to develop their work place policy for TB control and care and help them to implement the policy
- The TB partnership members should also support such factories to access the benefits of the ESI scheme which is already well linked to RNTCP.
- After initiation of treatment, patients should be encouraged to report to the provider, if they are leaving the area, to transfer treatment to the nearest centre to ensure continuity of treatment. These measures will help to reduce default on account of migration and achieve the desired outcome in RNTCP
- A national level strategy and guideline for TB care and control for migrant population is a strongly felt need

i.iv: MDR-TB:

- Further **expansion of DST laboratories** is necessary and it is possible that this could be done through a public-private partnership mechanism. This is already happening and we commend the foresight shown, however we recommended that the process be taken up further and with greater urgency.
- **Training of TB frontline workers and district level civil society organisation** on MDR/XDR TB could increase the early recognition of potential drug resistant sub-population and would enhance the selective DST strategy currently adopted. Also with greater patient education it would be possible to reduce the time lag in the detection of treatment failures. This can be done through the civil society engagement.
- Need to address the challenges that are emerging due to TB-HIV. ( see recommendations under TB-HIV)
- The **promotion of infection control and prevention measures** both at TB Care facilities but also at a household level. Low cost infection control protocols exist for both settings. However a greater emphasis and implicit strategy needs to be adopted. The need for this is specially great in the private sector which is largely unregulated. Manuals for training and IEC materials can be developed by civil society partners.
- It would be important to **expand the monitoring and information systems of the RNTCP to include private health care facilities**. It is important that information regarding diagnosis and treatment protocols even in the private health sector at least in the private medical colleges, private hospitals and nursing homes be collected. Advocacy on the need to comply with standard protocols would be necessary. Also under the hospital establishment acts, these institutions must be mandated to provide regular information about infectious



diseases including tuberculosis. CSO could play the intermediary role of advocates for this cause.

## **II. ACSM**

- Engaging policymakers, government officials at national and state level, all stakeholders in health care delivery, religious leaders, community leaders, patients and their families through strategic communication in bringing about behavioural and social change
- National programme to ensure ongoing support states to develop mechanisms to collect and analyze data, particularly in non-compliance pockets at sub-national level and develop interventions to address these reasons
- Centralization of IEC resources on ACSM possibly as a software link for member NGOs to use
- Regular certificate programs on ACSM training to be scheduled in batches for members
- Civil Society to ensure that NGOs/ CBOs are aware of RNTCP NGO schemes in terms of nature of scheme, eligibility and mode of access.
- Induction of NGOs into the program should have clear guidelines and signed MOUs in place
- Development of a TB ASCM (e) newsletter from public side to capture best practices and a column for addressing the challenges faced.
- Train workers on use of updated monitoring forms, and immediate social data training for States/district
- Develop and implement tools for assessing needs, planning, training, research and evaluation
- Integrate qualitative and quantitative data on ACSM's contribution to TB control which could be an evidence base for ACSM for TB
- Encourage people affected by TB and those treated patients to be engaged as spokespersons in all facets of national TB programme in local context
- Identify and reach underserved populations through focused Communication and Social Mobilization initiatives
- Ensure adequate staffing and capacity tailored to specific needs
- National level ACSM reviews in order to help country define challenges and identify ways forward
- Ensure that the findings from the research (OR) helps the program to come up with a clear cut strategy for the under- served.
- The challenge of reducing stigma and discrimination needs to be addressed within public and private health sectors and among health workers.
- Role of media in TB care and control need to be addressed in the RNTCP guidelines

## **III. PPM:**

Further inputs are necessary for guiding the national strategy on expansion of the existing PPM schemes. The reasons for low uptake require further information gathering which might suggest the revision of the schemes. It is very necessary to differentiate the cadres of private service providers into formal (allopathic, non-allopathic, pharmacies) and the non-formal (other traditional healers

and quacks). While additional information is required on the following points before arriving at any conclusion in strengthening existing PPM programs, piloting of some PPM on a limited scale is recommended.

#### **i.i: Studies**

- Treatment seeking behavior of the urban poor
- Reasons for the successful implementation of PPM schemes in some areas and low uptake in others.
- Understanding practice patterns of the non-formal service provider
- Prescription audit in certain areas for prioritizing PPM

#### **i.ii: Pilot programs**

1. Strengthening of training programs with innovations (incentives such as vouchers reimbursements, CME credits etc)
2. Branding of Good Private service provider
3. Involvement of the non-formal preferred provider

#### **Conclusion:**

While the challenges of TB care and control are multidimensional, it is important to strengthen the community response and make the community voice heard against the threatening TB epidemic of the country through meaningful and effective participation of the CSOs. With the shift to universal access of TB care, the role of CSOs will become more critical in terms of consolidating and scaling up those key community linkages with the essential services, especially in the underserved, difficult-to-reach areas and with marginalized, criminalized and migrated population groups across the country. There is also huge task and challenge to link the non-formal and private healthcare providers effectively to the National TB Program.

The RNTCP phase III should be the extended opportunity for the CSOs to enter into the true era of universal access where challenges will be more broad-based. The coordination, collaboration and solidarity within the TB partnership will become pivotal to meet those challenges in comprehensive and effective manner and add true colour to the RNTCP.