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

BACKGROUND:

RNTCP:

The Revised National Tuberculosis Control Programme (RNTCP), being implemented through the general health system under the umbrella of National Rural Health mission (NRHM), has made great strides in the past several years. The Programme has been consistently achieving global targets for new smear positive case detection (NSP CDR) (70%) and treatment success (85%), in line with the Millennium Development Goals (MDGs).

The RNTCP is now aiming to provide universal access for total TB care. For the programme to go through the last mile in achieving universal access, the healthcare providers, both formal and informal, public and private, who were so far outside the programme, will need to be effectively involved.

CIVIL SOCIETY ENGAGEMENT:

HISTORY OF CSO involvement:

TB Control in India started as a civil society initiative. In 1921, Dr. A Lancaster 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. 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. State TB association sprung up in a number of states for supporting the TB control efforts of the Government. 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 The Union in India. The results of these collaborative efforts led to the formation of a National level 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 to harness the strengths of partners in various technical and implementation areas, and to empower affected communities in TB care and control. The partnership comprising of diverse partners include technical agencies, non-governmental organizations including coalitions for TB, community-based organizations, affected communities, corporate sector, professional bodies, media and academia.

The Partnership’s Steering Committee comprises of members from various partner organizations and standing invitees include the Programme 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 members.

To help in achieving the targets of universal access, the Steering Committee members advised the civil societies to identify challenges and suggest recommendations to be incorporated into the RNTCP Phase III planning. The process started with collection of data from all partners, compiling of collected data

2 Prahalad Kumar, Journey of Tuberculosis Control in India, Indian J Tuberc 2005; 52:63-71
and writing of a consolidated paper of recommendations. The recommendations were further voted on and action by civil society added to it by partners. A consensus was agreed during the National Consultative Meeting held in January 2011. This note is being submitted as the final paper to the Central TB Division for consideration and inclusion in RNTCP III planning.

PROBLEM STATEMENT: The steering committee identified three specific areas of challenge to RNTCP implementation

1. SERVICE DELIVERY: RNTCP SERVICES:

1.1: Basic DOTS: Despite achievement of global targets at the national level, there remains wide variation in performance across districts and States. There are several hard to reach and difficult areas in the country where delivery of services, presently inaccessible, will require innovative measures.

1.2: HIV-TB: Under the constant threat of rapid TB transmission to its 23 million estimated HIV infected population thereby accelerating mortality, RNTCP needs to increase detection and provide appropriate care to TB/HIV co-infected through increased cross referral between the TB and HIV programmes.

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). Unhygienic living conditions, lack of health facilities/policies in the unorganized sectors, malnutrition, alcoholism, smoking, strenuous work, misconceptions towards TB are critical factors that can lead to disease among the migrants. Studies reveal migration as a key reason for default.

1.4: MDR-TB: 3% of the new and 12-17% of the retreatment smear positive TB cases are Multi-Drug Resistant. India being home to 3.4 million people with tuberculosis and 1.9 million 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. The emerging threat of XDR TB, with severely limited treatment options makes the situation further dangerous.

2. ACSM:

Advocacy to secure financial resources and change policies, guidelines and procedures, Communication to increase awareness, influence social norms, create behavioral change and improve interpersonal communication between providers and people affected with TB and their families and Social mobilization to change norms, improve and expand community services by bringing groups together to act at community level, has been adopted world-wide. ACSM activities are means to address key barriers to TB care and thus, support the achievement of RNTCP goals. Thus, ACSM strategies need to meet four important 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 L.S. Chauhan, Drug resistant TB; RNTCP response, Indian J Tuberc 2008; 55:5-8
3. PPM:

With 70% of health care in India being provided by the private sector, it is of great importance that this sector be effectively engaged in the treatment of TB Control. The private sector includes those practising allopathic, AYUSH, traditional healers and pharmacists. Their involvement has been limited so far.

Large scale migrations from rural to urban settings leads the urban poor accessing TB treatment for through private pharmacies and non—allopathic practitioners. With unregulated treatment practices, the MDR and XDR TB cases emerge as a threat to successful TB treatment programmes. Coupled with the stigma to HIV-TB cases (which make these patients seek treatment in the comfort and anonymity of these private sector providers) it has become ever so necessary to effectively include the preferred providers of the urban poor for strengthening the TB programme in India.

Recommendations for Service delivery

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<th>Top 5 Challenges</th>
<th>Recommendation</th>
<th>Actions by Civil Society</th>
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| 1. Reaching vulnerable populations and underserved areas for Universal Access    | ▪ Periodic Mapping at District/TU/PHC level to identify underserved areas  
▪ Devise/Allocate special incentives for difficult and underserved areas to patients and care providers, including CSOs  
▪ Alignment of TUs to NRHM blocks and revision of TU schemes to increase CSOs TU management  
▪ Identify & incorporate migrants as a special chapter in the plan  
▪ Incentivise homeless patients and CSOs to ensure diagnosis, treatment and care | ▪ Identification/ Mapping of the underserved areas  
▪ Implement incentive based innovative models of care delivery (e.g. conditional cash transfers based on the experiences of NRHM JSY)  
▪ CSOs to take up TUs  
▪ Develop innovative models of service delivery to the Migrants and Homeless, to promote adherence while migrating across state, district and international borders |
| 1.1 Addressing Migrants and Homeless                                             | ▪ Revise schemes with budgets for effective transport  
▪ Involvement of private labs in efficient collection, transport of specimens and tracking/dissemination of results | ▪ CSOs to run sputum collection centres in remote/difficult terrain, urban slums and other settings where access to microscopic and molecular diagnostics (including diagnosis of drug resistant TB) is sub-optimal |
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<th>3. Counselling in TB programme</th>
<th>• Mandatory Counselling using patient charter at DMC/PHC with specific budget and deliverables</th>
<th>• Undertake counselling of patients with available resources</th>
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<td>4. Low TB awareness among PLHIV networks</td>
<td>• Work through Intermediary NGOs for capacity building and mentoring of the PLHIV networks</td>
<td>• Intermediary NGOs and CSOs will sensitize and capacitate PLHIV networks in scheme adoption</td>
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<td>• Directly work with PLHIV networks through suitable schemes</td>
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<td>5. Active Case Finding</td>
<td>• House hold contact investigation to be included with higher incentives in ‘Adherence’ scheme</td>
<td>• CSOs will assist in conducting contact investigation</td>
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<td>• Active case finding for high risk groups by incentivising DOTS providers’ scheme.</td>
<td>• CSOs to implement active case finding strategies among HIV and other vulnerable populations.</td>
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<td>• Planned roll-out of intensified TB case finding activities in all HIV care and support facilities.</td>
<td>• Implement active screening of health care seekers at all health facilities.</td>
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<td>• Actively screening health care seekers at all health facilities.</td>
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<td>Other Challenges:</td>
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<td>6. Health Insurance Schemes covering TB</td>
<td>• Engage with public and private sector health insurance entities to establish norms and standards for insurance coverage of TB patients based on the principles of quality detection, diagnosis, treatment and notification.</td>
<td>• Advocacy for initiatives with insurance authorities</td>
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<td>7. Sustaining technical expertise and motivation among health care staff</td>
<td>• Orientation and refresher trainings for Health care staff (bottom up) by CSOs</td>
<td>• Conduct training on soft skill development of key RNTCP staff</td>
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<td>• Motivate staff by recognition/awards</td>
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<td><strong>8. Greater flexibility in RNTCP guidelines</strong></td>
<td><strong>Ensuring flexibility in diagnosis, treatment and care</strong></td>
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<td><strong>Participate in revision/evolution of RNTCP technical and operational guidelines to bring perspectives of the affected community, patients and a range of front-line care providers.</strong></td>
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**Additional discussion points and recommendations from the group on “Service Delivery”**

- Roles of CTD and Civil Society need to be agreed upon in taking the recommendations forward.
- NGO schemes under RNTCP to be revised and designed by civil societies (Users)
- Delegation of decision making on allotment of NGO schemes to District health administration (for all schemes)
- To ensure effectiveness and efficiency and accountability – joint MIS (with NRHM) to be developed with better set of tools
### Recommendations for ACSM

#### Top 5 Challenges

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<td>1. Political will varies from state to state and hampers successful implementation of RNTCP</td>
<td>▪ Sensitization and Advocacy</td>
<td>▪ Advocacy with elected representatives/parliamentarians to increase political will</td>
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<td>▪ State Report card by The Partnership</td>
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<td>▪ Facilitate and support formation of a National level patient network</td>
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<td>▪ Capacity Building of staff in ACSM planning, implementation and monitoring</td>
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<td>▪ Identifying context-specific ACSM strategies addressing local challenges</td>
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<td>2. Distribution channels of IEC material</td>
<td>▪ Proper distribution and dissemination of IEC material</td>
<td>▪ Development of key messages for target groups</td>
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<td>▪ Patients' Charter for TB Care to be made available in local languages</td>
<td>▪ Facilitate distribution and dissemination and provide feedback about community response</td>
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<td>▪ Role of DOTS providers to include IEC dissemination at strategic locations</td>
<td>▪ Establish two-way distribution channels</td>
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<td>3. Recognition and acceptance of CSOs by the local government</td>
<td>▪ Joint sensitization and advocacy to increase the visibility of ACSM efforts</td>
<td>▪ Joint efforts by RNTCP and CSOs to sensitize the local authorities</td>
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| **4. Inadequate operational research and lack of documentation of innovative and good practices** | ▪ Increase operational research and integrate into national Programme  
▪ Tools for monitoring, evaluation and research  
▪ Improved data management at state-level for designing programmatic interventions for ACSM.  
▪ Increased participation and ownership by institutions known for research | ▪ CSOs can assist in implementing OR  
▪ Enhance technical capacity of CSOs to conduct research and develop /adapt M & E tools  
▪ Active patient participation in designing and execution of OR.  
▪ Support to local patient groups to conduct community mapping exercises for further studies and community mobilisation |
|---|---|---|
| **5. Low visibility of the network of cured TB patients** | ▪ Establishment of a national SMS Hotline for People with TB to be managed by cured patients  
▪ Local social mobilisation through SMS technology | ▪ Engagement of cured patients of TB as advocates to the community.  
▪ Partnership facilitates the formation of associations at all levels, with proven models of peer education as a strategy (ex TB Care Groups and Forums) |
| **Other Challenges;** |  |  |
| **6. Role of media in TB care and control is not strategic** | ▪ Involvement of media with clear cut strategy and plan to partner with people living with TB  
▪ Advocacy for media support to be provided by the Govt. | ▪ Regular sensitization and follow up with media engaging patient representatives to be facilitated by Partnership |
Recommendations on Public Private Mix

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<td>1. Low uptake of the existing PPM schemes by private providers</td>
<td>• Study to understand the reasons. Of low uptake</td>
<td>• CSO to undertake study and facilitate in uptake of schemes</td>
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<td>• Piloting new schemes (vouchers, branding, etc.)</td>
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<td>2. Sub-optimal Involvement of the non-formal service providers in urban areas</td>
<td>• Regular interaction with all non-formal PPs</td>
<td>• Sensitization, supportive supervision and monitoring by CSOs</td>
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<td>• Link them with tangible outcomes</td>
<td>• Facilitate broad based community mobilisation on drug issues, including incorrect regimens, counterfeit, non-Quality-Assured products etc.</td>
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<td>3. Incorrect regimes for TB treatment by private providers.</td>
<td>• Sensitization and advocacy</td>
<td>• IMA, Pharmacist and other associations to take the lead on orientation and sensitization on RNTCP guidelines.</td>
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<td>4. Over the counter prescription of TB treatment by pharmacist and unlicensed service providers.</td>
<td>• Legislation for selling TB drugs over the counter</td>
<td>• Advocacy with elected representatives/parliamentarians for legislation</td>
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<td>5. Unregistered cases with private sector</td>
<td>• Identify a process to institutionalise ‘Notification’ by private practitioners</td>
<td>• Develop and implement market based models for notification of all TB cases by medical practitioners using mobile phones, conditional cash/credit/loyalty-points transfers, vouchers, etc.</td>
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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.
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