Target TB India Programme Evaluation 2010-2014

Dr Dennis Pain
ACTS Consultancy Ltd
www.acts-consultancy.com

Praxis
Institute for Participatory Practices
www.praxisindia.org

31st March 2014

Table of Contents

1. Abbreviations and acronyms 3
2. Basic Information 4
3. Executive Summary 5
4. Background 6
   - 4.1. Institutional Challenges 6
   - 4.2. About Target TB 6
   - 4.3. Z`Summary of the DFID CSCF funded Target TB Project 7
   - 4.4. Expected project outcomes 7
   - 4.5. Intervention Area and Modality 7
   - 4.6. Odisha and Jharkhand: 8
   - 4.7. Tamil Nadu, Theni District: 8
5. Evaluation Approach: 9
6. Impact and results: 10
   - 6.1. Overall: 10
   - 6.2. Health Seeking Improvements 12
   - 6.3. Awareness 13
   - 6.4. Community Empowerment 15
   - 6.5. Discrimination 16
   - 6.6. Service Provision Improvements 16
   - 6.7. Jharkhand/Odisha results in TB detection and cure: 19
7. Logframe Indicators 19
8. Empowered target groups and Project Accountability: 19
9. Value for money (VfM): 20
   - 9.1. Effectiveness 20
   - 9.2. Efficiency 20
   - 9.3. Economy 21
10. Innovation 22
11. Sustainability 22
12. Realisation of Risks 22
13. Contribution to CSCF Objectives 23
14. Contribution to the Millennium Development Goals 23
15. Lesson Learning 23
   - 15.1. Approaches to Empowerment and Advocacy 23
   - 15.2. Equity 23
   - 15.3. Capacity building 23
   - 15.4. Monitoring & Evaluation 24
16. Recommendations 24
17. Annexes (Annexe A: Achievement Rating Scale; Annexe B: Return to Investment) 25
   - 17.1. Logframes; Evaluation ToR & Plan; Declaration; 25
18. Annexe B: Return to Investment 26

1. Abbreviations and acronyms

AA	Arogya Agam
AID	Alternative for India Development
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
AWW	*Anganwadi* Worker[1]
BCG	Bacillus Calmette–Guérin vaccine against TB
BPL	Below Poverty Line
CSCF	Civil Society Challenge Fund
CSO	Civil Society Organization
DACT	Development Action Consortium Trust
DFID	Department for International Development (UK)
DMC	Designated Microscopy Centre
DOTS	Directly Observed Treatment, Short-course
DTO	District TB Officer
FGD	Focus Group Discussion
GKS	Gaon Kalyan Samiti, equivalent to VHSC
GoI	Government of India
ICDS	Integrated Child Development Services
MAAS	Maharashtra Association of Anthropological Sciences
MBT	Mycobacterium Tuberculosis
MDG	Millennium Development Goal
MDR	Multi-Drug Resistant
MMS	Mahalir Munnetra Sangam
MoU	Memorandum of Understanding
NGO	Non-Governmental Organization
PAP	Poorly Accessible Panchayat
PHC	Primary Health Centre
PLWHA	Person Living With HIV/AIDS
PRI	Panchayati Raj Institution
RNTCP	Revised National TB Control Programme
Rs	Indian Rupees
SC	Scheduled Caste (*Dalit*)
SHG	Self Help Group
SRED	Society for Rural Education and Development
SMART	Specific, Measurable, Achievable, Relevant and Time-bound
ST	Scheduled Tribe (*Adivasi*)
STO	State TB Officer
TDNP+	Thanjavur District Network of HIV Positive People
TB	Tuberculosis
VHN	Village Health Nurse
VHSC	Village Health & Sanitation Committee
WHO	World Health Organisation

[1] The *Anganwadi* Worker, selected from the local community, is a community based frontline honorary worker of the ICDS scheme under the Ministry of Women and Child Development – see http://wcd.nic.in/icds/icdsteam.aspx

2. Basic Information

Project Title:	Promoting Equal Access to TB Health Services in India: CSCF 502
Agency:	Target Tuberculosis India, with a focus on the most marginalized social groups and communities in (i) States of Jharkhand (Districts of East & West Singhbhum); and Odisha (Mayurbhanj District); (ii) Tamil Nadu State (Theni District)
Partners:	for (i) Alternative for India Development (AID); and for (ii) initially DACT (Development Action Consortium Trust) and from July 2012 coordination replaced by one of the consortium members, Arogya Agam (AA), working with the 5 other NGOs (Vasanatham, Mythri, SRED, TDNP+ and MMS);
Project Budget:	£479,223
DFID Budget:	£479,223
Evaluation Budget:	£ 15,170 or 3.2% of Project Budget
Evaluation:	**Team Leader & Report Writer: Dr Dennis Pain, ACTS Consultancy Ltd** (see www.acts-consultancy.com), also responsible for evaluation research plan and leading initial evaluation meetings with partner agencies and government officials from the Revised National TB Control Programme (RNTCP) **Field Research & Field Reports: Praxis** (Institute for Participatory Practices, with offices in New Delhi and Chennai – see www.praxisindia.org), including responsibility for design and delivery of sampling, questionnaire and Focus Group Discussions in the field: **Dr Moulasha**, assisted by Stanley (Tamil Nadu) **Sharmistha** assisted by Jyoti (Jharkhand/Odisha)

Evaluation as set against the Aug 2010 Triple Line amended version of the Logframe (and a further revision for Tamil Nadu of May 2011) and carried out in the field during Feb 2014.

3. Executive Summary

Alternative for India Development (AID) and Arogya Agam (AA), in partnership with Target Tuberculosis (Target TB), received nearly £480,000 from DFID's Civil Society Fund to implement a four year project entitled 'Promoting Equal Access to TB Health Services in India". The Evaluation has been carried out in February 2014 by ACTS Consultancy, working with Praxis. The project aimed to ensure marginalised and poor communities were able to exercise their right to access quality TB health services, through promoting and strengthening the role of civil society groups in positively influencing RNTCP policies and programmes. It has been implemented by AID and AA staff and five NGO partners of AA, through community based groups and local governance structures at community level in some of the least accessible Panchayats in Jharkhand (East & West Singhbhum districts), Odisha (Mayurbhanj district) by AID and in Tamil Nadu (Theni district), managed by Arogya Agam. The Jharkhand & Odisha project operates in remote forested hilly border districts where most are tribal people and Naxalite insurgency endemic. Theni District has a majority of Scheduled Caste and Most Backward Castes. All districts have high levels of out-migration of labour working in agriculture, quarries and brick-kilns and Theni has many who are living with HIV. Most are marginalized by remoteness, language, poverty or sexual identity and health services have been poor in quality and staffing, with high levels of TB unidentified and untreated. **The returns to investment of the project are 38% p.a. over 20 years.**

Over four years, the project has empowered women's self-help groups, Panchayati Raj Institutions and village health committees to engage on issues of TB, identifying possible patients and encouraging them to go for diagnosis and treatment and providing volunteers to monitor their treatment compliance. TB detection, treatment, compliance and cure have all risen significantly. The state Revised National TB Control Programme (RNTCP) has variously responded to local community and NGO demand by ensuring drug supplies, increasing staff and utilizing untied funds to assist patients and staff posted to difficult areas. Awareness of TB has been raised through radio, through women's Self Help Groups (SHGs) and through Panchayati Raj Institution (PRI) and local self-governance structures, as well as through training the locally recruited community level health staff such as the Integrated Child Development Services *Angadwadi* worker (AWW), the Auxiliary Nurse Midwife (ANM) and the Accredited Social Health Activist (ASHA). Together with the volunteers from the community, mostly from the women's SHGs or themselves former TB patients, they have improved access to services at the PHC (Primary Health Centre) level, but have not been institutionally integrated into the RNTCP service. Knowledge and behaviour relating to TB have changed and those infected spend less time and money on what many now know as useless traditional remedies or "quacks" and registered medical practitioners practicing alternative medicine. Community radio and cultural activities have increased project credibility in tribal areas and mistrust of formal provision has reduced. Following a clear policy, project workers, mostly recruited from the local area, are able to work freely in Naxalite affected areas and have the trust of all parties – government, opponents and communities. There is still work in progress, particularly with regard to integrating community level demand with the top down RNTCP, although the tide of TB infection has been reversed and awareness is much higher. More needs to be done to achieve this integration and the use of community radio should be extended and new forms of mobile connectivity developed that will enable RNTCP to become more accountable and responsive.

Recommendations cover epidemiological research; death registers and death audits; use of ASHA and AWW integrated into the RNTCP and that of volunteers; use of incentives to increase treatment compliance and health service provider behaviour; BCG immunization for children; continued NGO capacity building at the community level; and influencing UK private sector through its corporate social responsibility.

4. Background

Tuberculosis, Mycobacterium Tuberculosis (MBT), or TB is a common and in many cases fatal infectious disease that typically attacks the lungs, but can also affect other parts of the body. Despite being preventable and curable, nearly two million people die every year from it, making the disease one of the biggest killers in the world and a target for the MDGs. According to the WHO Global Health TB Report of 2008, India had the largest number of people with TB with 1.9 million cases, which killed more than 300,000 per year while accounting for 21% of the global rate. TB can be hard to detect, with no visible symptoms among dormant carriers, and is infectious among human beings. In a country like India, the link between TB and poverty is insidious. Poverty is both a cause and effect of TB, creating a poverty-disease cycle. Malnutrition and poor living conditions increase people's vulnerability to TB. Whilst TB tests and treatment are free through the national TB control programme, lack of available services in some areas, and lack of ability of people on low income to afford time off work or to pay for transport, limits access to such services. On average, at programme inception, it was estimated that people spent Rs. 2,500 on private advice and medication before getting a proper diagnosis[2]. Delays in seeking treatment can lengthen recovery times, meaning more time off work, greater loss of income and distress sales of remaining assets. Social exclusion also impacts upon TB services. Marginalised people such as tribal groups living in remote forest villages lack basic information on TB and are isolated from health services. PLWHAs (People living with HIV/AIDS), who have been estimated globally to be thirty times more likely to contract TB than someone who is HIV negative, also face high levels of stigma and discrimination in accessing services. When poor families have to make decisions about best use of limited resources, women, girls, disabled people and the elderly are less likely to receive and/or seek treatment. In many states, especially, Eastern and Southern India, TB awareness remains low, mortality rates high, and quality of service poor, particularly among poor and marginalised groups such as tribals, dalits and women, especially those who are unskilled migrant labourers. Hence, while TB control is the overall objective, it becomes even more important to reach out to these more vulnerable and marginalised groups.

4.1. Institutional Challenges

There is a national level TB control programme under the Government of India known as the RNTCP (Revised National TB Control Programme), but, as in many high TB burden countries, it is under-resourced and Civil Society Organisations (CSOs) play a key role in complementing government efforts. Lack of funding, poor capacity building, centralization of authority within the RNTCP and poor coordination are some of the reasons why CSOs had not been able to engage successfully with RNTCP in programme implementation and policy-making.

4.2. About Target TB

Target TB was established in 2003 in response to the global TB emergency. It supports some of the poorest and most vulnerable people in Africa and Asia to access quality TB testing, treatment and vital support services. Target TB works in areas where health facilities are poorly developed and government services are under pressure to meet demand. Aiming to strengthen existing health systems, all of Target TB's partners work in collaboration with National TB Programmes and promote the World Health Organisation's standard method of treatment for TB, Directly Observed Treatment Short-course (DOTS).

[2] Target TB CSCF Proposal 'Promotion of Equal Access to TB Health Services in India'

Target TB currently works under variously funded programmes with five partners in India to support TB control initiatives in Tamil Nadu, Uttarakhand, Jharkhand and Odisha (formerly Orissa) States.

4.3. Z`Summary of the DFID CSCF funded Target TB Project

Alternative for India Development (AID) and Arogya Agam (AA), in partnership with Target Tuberculosis (Target TB), received a grant from DFID's Civil Society Fund to implement a four year project entitled 'Promoting Equal Access to TB Health Services in India". The project aimed to ensure marginalised and poor communities were able to exercise their right to access quality TB health services, through promoting and strengthening the role of civil society groups in positively influencing RNTCP policies and programmes.

The programme has been implemented by AID and AA staff and five NGO partners of AA, through community based groups and local governance structures at community level in some of the least accessible Panchayats in Jharkhand (East & West Singhbhum districts), Odisha (Mayurbhanj district) by AID and in Tamil Nadu (Theni district), managed by Arogya Agam (AA – replaced Development Action Consortium Trust (DACT) in June/July 2012). A twin-track approach was used: on the **demand-side**, building the skills of staff within AID, AA, partner NGOs of AA and of the community based groups and local governance structures in advocacy, lobbying, influencing and monitoring of TB services, increasing their overall voice, legitimacy and credibility, and, on the **supply-side**, supporting improved functioning of district and state level RNTCP systems as a result of increased government responsiveness.

Other outputs include increased learning on best practice with regard to civil society engagement and also an element of increased UK public awareness. Increase in UK public awareness will not be part of this evaluation. Baseline data was produced by AID and DACT.

4.4. Expected project outcomes

1) CSOs, representing vulnerable and marginalised groups, would develop the capacity to: engage and advocate with RNTCP to improve access to and quality of TB services; influence policy and practice; increase community awareness of TB.

2) The functioning of RNTCP systems would improve, enabling improved access to services for marginalised and vulnerable groups and more meaningful engagement with civil society groups in RNTCP implementation, monitoring and policy formulation.

3) Increased learning on best practice and the positive impact of civil society's engagement and role in TB prevention, control and service delivery.

4.5. Intervention Area and Modality

- The project covers three states – Jharkhand (2 districts, 10 panchayats in each), Odisha (1 district, 10 Panchayats) and Tamil Nadu (1 district, 60 panchayats - 30 of them difficult-to-access areas)
- The interventions in Jharkhand and Odisha were implemented by AID, through project staff interacting directly with the communities and the government.
- The intervention in Tamil Nadu was implemented by a consortium of five partners, led initially by DACT (Development Action Consortium Trust[3]), an umbrella organisation, and subsequently by AA (one of the original five partners).
- Baseline studies for the three states were completed; however the format used for Jharkhand-Odisha was different from the one used for Tamil Nadu[4], providing problems in comparing interventions across the two areas for all indicators. However, in all states, the common aspects include monitoring service gaps, establishing dialogue between community

[3] DACT, as an organisation generated by the implementing partners in the Theni consortium, had to be wound down because it was unable to sustain itself

[4] The formats were different because both AID and DACT commissioned and managed the baselines separately

and service providers/Govt at each level and participating in Primary Health Centre (PHC) TB programme reviews. Moreover, due to the nature of the target groups in each area there were differences in the type and nature of interventions in Tamil Nadu and in Orissa-Jharkhand.

4.6. Odisha and Jharkhand:

The DFID-funded Target TB Project focuses on two predominantly tribal (Adivasi) regions, East and West Singhbhum districts in Jharkhand and Mayurbhanj district in Odisha. The East and West Singhbhum districts are among the worst five districts of Jharkhand for TB prevalence, contributing nearly 14% of the cases registered (Kulkarni & Kudale et al., 2014)[5]. Apart from the lack of information, and poor organizational reach, there are several other social, economic and physical barriers to be overcome in both the focus areas. Earlier interventions had not recognized the different lifestyle and cultures of Adivasis, as well the fact that they have their own practices using traditional healers and witchcraft, which made this particular demographic hard to penetrate. Naxalite insurgency activity, involving five separate Maoist organisations and possibly 3,000 cadres, is also endemic, creating access problems for officials and patients. Over time, their dynamics have changed with the entry of criminal elements extorting protection money or "*rangdhari* tax" from infrastructure contractors, corporates and corrupt politicians, as well as fines on non-performing teachers with annual collections valued at nearly US$24 million (e.g. see Times of India for 14 Feb 2014, page 4). They operate mostly in remote and dense forest areas, which government has notified as "disturbed districts". In Jharkhand, out of the 24 districts, 20 districts are officially notified as "disturbed". Over 20 years earlier, their focus was on feudalism and landlordism, evicting the landlords in villages through armed uprisings and mass mobilizations and establishing their domain in the name of "liberated villages". Naxalites have never been reported threatening immunisation days.

Implemented by AID, which has been working in the area for about 25 years, the TB programme intervention has been with tribal populations, including tribal self-governing structures, PRIs and SHGs, with special emphasis on tribal communities and women; focused on advocacy initiatives, emphasising working through VHSC (Village Health & Sanitation Committee), GKS (the Gaon Kalyan Samiti equivalent to VHSC in Odisha's tribal areas[6]), PRIs and also through tribal self-governing structures for optimisation of available schemes and programmes for patients, such as use of untied funds (Rs 10,000 to each health committee) for TB to support compliance/adherence strategies, supporting transport to access treatment, assistance in availing Below Poverty Line (BPL) cards, improving access to medicines, incorporating TB in the Tribal action plans, etc; and engaged with existing District and State Level networks with the aim of strengthening the voice of CSOs to advocate for improved functioning of the RNTCP.

4.7. Tamil Nadu, Theni District:

Theni District was formed by the bifurcation from Madurai District in 1996. Located in Southern Tamil Nadu, the district lies at the foot of the Western Ghats. According to the 2011 census, Theni district has a population of 1,243,684. The district has a population density of 433 inhabitants per square kilometre (1,120 /sq mi). Its population growth rate over the decade 2001-2011 was 13.69%. Theni has a sex ratio of 990 females for every 1000 males and a literacy rate of 77.62, higher than the national rate. Its economy is mostly agricultural. Utilization of land area for cultivation in Theni district is 40.33%. The principal crops cultivated here are sugarcane, cotton, rice (paddy), millets and other cereals, pulses, groundnut, ginger, silk banana, coconut, tea, coffee, cardamom, grapes and mangoes.

[5] Kulkarni & Kudale et al. (2014). Situation Assessment of Tuberculosis in hard to reach tribal areas of Jharkhand [online]: http://www.researchgate.net/publication/260353715_Situation_Assessment_of_Tuberclosis_in_hard_to_reach_tribal_areas_of_Jharkhand [Accessed: 24 March 2014]

[6] See http://www.nrhmorissa.gov.in/writereaddata/upload/documents/gks-pd.pdf accessed 27 March 2014

Theni district consists of eight blocks and AA and its five partner NGOs (Arogya Agam, Vasanatham, Mythri, SRED, TDNP+ and MMS) cover all the blocks for the Target TB Tuberculosis programme. There are 31 poorly accessible panchayats (PAP) with 40 potential panchayats were selected on the basis of poor health services, tribal or forest areas, exceptionally remote villages, distance from PHC etc. The intervention has been primarily with PRIs and SHGs, with a special attention to Dalits and HIV positive groups. It has also facilitated the formation and strengthening of reinvigorated VHSCs, although the evaluation review found that these were not actively linked to the PRI, with a notable exception where the PRI President was also a member of the VHSC. The Theni programme has set up district and state level TB networks that submitted petitions against shortages of medicine and staff, appealed to address backlogs in detection, and signed MoUs with the government for effective monitoring.

In each PAP the programme formed one village health committee to address the issues related with RNTCP services. They periodically convene meetings and discuss major issues that relate to health, not only TB but also issues such as waste water, drainage and dengue, and, if it needs special attention, they will act and serve notice on higher officials.

The Target TB programme in Theni, between April 2010 and March 2014, has referred, tested and diagnosed almost 5242 TB patients and more than 84% were followed up for DOTS and rest of the patients were followed up by the Village Health Nurse (VHN) or through public health facilities. Currently Theni has 16 additional PHCs and in all the PHC the programme conducted linkage meetings and the Village Health & Sanitation Committees (VHSCs) were linked to ensure the sustainability of the programme, at least with regard to accountability of sustained service provision in line with RNTCP guidelines. At the district level there is a strong federation and this also linked to the district head quarters hospital/RNTCP officials to provide better services of RNTCP among 31 PAPS. Prior to the programme, MDR TB cases had been increasing with 19 cases in Theni district. Advocacy with district officials led to an MDR TB testing centre being started at Madurai Government Hospital for the eight districts of the state. The programme influenced other CSOs and AA partner NGOS to take up RNTCP related programmes in the district and in the third year, four CSOs/Partner NGOs started DOTS Monitoring Centres (DMCs) and in the current year it increased to five. The programme has also been involved in the setting up of the Tamil Nadu Tuberculosis Control Network, launched in Chennai in Feb 2014, to improve the RNTCP services in the state. The network will advocate with higher officials in the state and also in the country towards improved RNTCP/health services.

5. Evaluation Approach:

The planned approach used in the two areas was modified to take account of the district realities, with a large all-day initial evaluation meeting in Theni with representatives of RNTCP, front line health workers, TB patients, women's SHGs, PRIs and implementing organisations, but only a meeting with AA district coordinators (5) and field staff (15) in Jamshedpur, since patients are more scattered in remote locations in the three Districts. Stratified sampling was also adjusted by the team to reduce travel between interview locations while ensuring adequate random coverage of the four districts: in Theni - three Blocks (one AA and two other partners, one having large numbers of TB patients and the other many PAPs; four PAP villages/PRIs were then selected and five non-PAP villages and three villages as a control group. Evaluators selected a random sample from these villages using the agency/RNTCP list of patients from April 2012 to July 2013 to be interviewed, together with the control sample of households taken from the Panchayat BPL list. Care was given to include respondents from all caste groups. The Theni survey sample had 48 TB Patients and 17 Control (all non-TB) respondents. The Theni data collection was conducted from 10th to 19th February 2014.

Three kinds of Interview schedules were constructed for interviewing the patients; household members of patients; and the control group. Guidelines for Focus Group Discussions were drafted for discussions with women sex workers, Trans Gender community, Community Support Organizations, Village Health Committee and DOTS volunteers. Guidelines were worked out to interview the service providers, such as the RNTCP staff and the Village Health Nurses (VHN). Case reviews were completed on patients who had died of TB.

In Jharkhand/Odisha, with six blocks covered by the programme in three Districts and using a full list of all patients in these blocks, the sampling design sought a mix of recent patients across the Blocks, majority from programme hamlets and some from a near-by non-programme "control" hamlet where AID works, adding some pre-2010 patients and non-TB respondents as controls. In practice, 43 patients from programme areas were interviewed across the three Blocks of Mayurbhanj District in Odisha and 11 persons were interviewed as the "control" group from four Blocks – seven of whom are, or were earlier, TB patients and four were never diagnosed with TB. In Jharkhand, 48 patients were interviewed from nine Panchayats of three Blocks in East and West Singhbhum, with 19 persons interviewed as a "control" group from four Blocks – 12 of whom are or were earlier TB patients and seven were never diagnosed with TB.

The totals covered by the survey instrument were 139 TB patients in programme areas and 19 past or present TB patients not reached by the programme and 28 persons who had never been diagnosed with TB. 48% of the Jharkhand TB patients interviewed lived more than 10km from a TB health facility, but for many in Odisha it is 40-60km away. Language-based tribes and Adivasis represented around 90% of the TB patients and 74% of the "control" in both Odisha and Jharkhand and male-female respondents were in the ratio of 2:1 overall in Jharkhand and 4:1 in Odisha, reflecting respective prevalence around 3:1.

The individual questionnaires were backed by Focus Group Discussions (FGD) with key stakeholders. Overall FGDs were held with 13 DOTS volunteers; seven Transgender Group members; seven from a Women's Federation; seven from a Village Health Committee; three RNTCP staff (an MDR-TB Supervisor and two Senior TB Supervisors). Individual interviews were held with a District TB Officer; a Health Visitor; a female sex worker with HV co-infection;

6. Impact and results:

6.1. Overall:

In the tribal areas of Jharkhand and Odisha, social constraints on TB treatment take-up were not caused by discrimination, which was low as it was in Theni (where 92% said there was no discrimination against TB patients at home or community levels, although it was reported as very different a decade ago when family members saw it as a dangerous disease), except for discrimination against some minority tribes marginalized by dominant tribes. The main constraints on treatment take-up in the tribal districts are lack of basic knowledge of symptoms, excessive consumption of local *Hadia* liquor and tobacco (also reported as a problem by RNTCP staff in Theni), the distance and cost of reaching PHCs and the norm of going to local herbalists and *ojha* "witch-doctor"/diviners[7] and also to unqualified medical "quacks" who tend only to refer patients when they have spent all their reserves. There are

> Sanju Munda, 20 years old from Jharia village of East Singhbhum, with extra pulmonary TB and a swelling infection in her neck, initially visited the private doctor and paid for medicine until her money was over and she could not continue the treatment. When she came to know from the ASHA (Accredited Social Health Activist) that free treatment is available, Sanju took medicine from the ASHA and finished her course on time.

[7] See, for example, Ajit Dalal "Folk wisdom and traditional healing practices: Some lessons for modern psychotherapies" in Foundations of Indian Psychology 5-4 of 30 June 2007 http://www.ipi.org.in/texts/ajit/dalal-folk-wisdom.pdf accessed 27 March 2014

examples in some communities where the traditional healers, admitting that they have no cure for TB, have agreed to refer patients to PHCs.

In one sample "control" village, a TB patient, who had discontinued DOTS treatment, preferring a local herbalist, agreed after advice to go the next day to the PHC. 62.5% of TB patients in Jharkhand (72% in Odisha) got proper diagnosis in less than 3 months from first symptoms, with 19% (9% in Odisha) between 3 to 6 months and 15% (14% in Odisha) over 6 months. In Theni, 70% sought their first consultation at a local hospital or health facility and 30% with private doctors and pharmacists, showing a much higher level of trust in and access to the formal health sector.

Cost incurred before proper diagnosis of TB

Private cost incurred before getting proper TB treatment (in percent)

In Rupees	Percent	
	Odisha (Jharkhand)	Theni
No expenses	26 (18)	23
1 to 1000	19 (19)	33
1001-2000	5 (6)	
2001-3000	7 (15)	21
3001-4000	2 (17)	
4001-5000	5 (6)	
5001-6000	2 (8)	
6001-7000	7 (4)	
7001-9000	- (4)	
10000-49000	26 (up to 13,000)	18 (up to 50,000)
Over	2.4 (2.1)	

A quarter of the Odisha patient sample (and similarly in Theni) report not having paid any money, while, at the other extreme, one patient reported spending between Rs. 50,000 – 60,000 (£500 - £600). Generally, Jharkhand patients pay more than those in the other districts before diagnosis. However, a quarter of Odisha patients did pay significantly more than the norm for Jharkhand patients, in the range of Rs. 10,000 to 13,000, and had to sell their livestock such as a cow or goat, which usually had been considered as family capital. The mean cost for those who did pay for alternative treatment prior to diagnosis was just over Rs 5,000 and the median cost was Rs 2,500. Overall, including those who paid out nothing before their free diagnosis in the PHC, the mean costs out of pocket were just under Rs 4,000 and the median cost was Rs 1,500. This can be compared to the overall pre-project patient spend of Rs 2,500 on private advice and medication before getting a proper diagnosis. **As a result of the project, awareness of available free diagnosis has saved the poor entering a devastating cycle of debt.**

> Madhav Naik who lives in Ghatkuanri village, Brahmangaon Panchayat or Bangriposha block, spent Rs 10,000 (£100) for his treatment. He had five goats and had to sell two @ Rs 5,000 per goat.
>
> Nagi Hansda, from village Chuapani of Nischinta Panchayat has been suffering from TB for a year. She continues to be confined to bed and unable to do work. 15 years ago, she had suffered from TB and after 4 or 5 years, her husband Govindo Hansda also suffered from TB. Economically, this family is very poor, taking casual labouring work for their livelihood. For Nagi Hansda's treatment more than Rs 8,000 has been spent within a year. Her son, who has migrated to West Bengal for agricultural work, took Rs 7,000/- back home which was all spent on her treatment. The family has now had to sell two goats. She is a Category-2 patient; therefore, she has to visit the Auxiliary Nurse Midwife (ANM) three times a week to have an injection. Being very weak, she goes by Auto, which costs Rs. 80/- per visit.

Poverty is common to all three programme districts, but, in Theni, all respondents were registered as BPL and 44% were not working at the time of the evaluation. Of those working, 30% were working as coolie labourers on daily wages and another 30% have their own business such as petty shop/tea shop or middleman, while 22% were not working regularly. However, prior to contracting TB, 81% were working, and most (64%) of them were working as coolie/daily wage earners, which clearly indicates a significant drop in the work force during and after treatment. Livestock and petty shops were owned by 13% and another 13% previously worked as a driver or electrician or factory worker. 44% of Theni patients are Scheduled Caste / Scheduled Tribe

(SC/ST) and another 14% belong to the Most Backward caste category. For those diagnosed in Theni in both 2012 and 2013, about half had been unable to work for the first three months following their first symptoms, with a one-third not working for nine months. 20% of Theni patients felt that their ability to work was currently worse than before diagnosis, but **over 50% felt that their health had improved and that they were fine and normal, without TB related problems, with improvement being confirmed by over 80% of the household members questioned. They were also more capable of daily activities, but one-third reported that, despite feeling better, they were unable to work as before. Their loss of earning potential pushes already poor households further into chronic poverty.**

According to project staff, the project has been able to prevent significantly Multi-Drug Resistant TB (MDR-TB) in the project region, with not a single MDR-TB being detected over the past year. On the other hand, the non-project areas such as Ghatshila recorded 22 MDR cases, according to the District TB Officer (DTO) of East Singhbhum. This is a strong indication of impact of project intervention. **During the inception stage of the project, the category-2 and Extra-pulmonary cases were close to 15-20%. Now this has been reduced to 7-8%. This illustrates the significantly improved TB scenario in the project sites.**

6.2. Health Seeking Improvements

Physical access to functioning services has improved with improvements in health provider behaviour and in health seeking behaviour. About half the patient respondents in Odisha (and Jharkhand) took only 15-30 mins to get to a treatment centre while a further quarter (40% in Jharkhand) take up to 2 hours, about half (nearly 40% in Jharkhand) by public transport and a quarter by cycle, but 14% (19% in Jharkhand) had problems reaching the treatment centre, mostly the prohibitive cost, averaging about Rs 300 in Odisha and less than Rs 60 in Jharkhand and only Rs 10-20 in Theni, where 94% reported no problems in reaching their treatment centre (although Theni RNTCP staff noted the difficulty of providing services in difficult hilly terrain, where patients tend to drop out of treatment). Financial support for transport from the community, who know the real cost for each location, can make a critical contribution to diagnosis and treatment compliance in Odisha at least. This is not so critical a factor in Theni, where 79% reported having services within 1-2km.

Early detection makes life easier for people who are working, since they do not need to stop working. During June to December months, as people come back to the villages for agricultural work, more TB cases are identified, but it has been a challenge to maintain their compliance as after the agricultural season they might go back to their respective place or migrate to some other place in search of work. Many of these places of work are high-risk environments, such as stone quarries, brick kilns and as woodcutters and Sal-tree leaf pluckers. Migration of men for work may be one reason why, in Theni, gender disaggregation of the full patient register shows a lower death rate and default rate among women. Analysis of the register also shows that the most oppressed, Arunthathiyar and other Scheduled Caste groups have fared better in their cure rate compared to other backward castes. **Overall the default rate and death rate have come down in 2013 from 2010 levels.**

Estimate the number of days that you were not capable of daily activities in a month (in percent)			
Before treatment		After treatment in the last one month	
1-4 days	30.2	0	34.9
5-9	2.3	1	44.2
20-24	14	3	4.7
25-29	20.9	7	11.6
30+	30.2	9	2.3
Not applicable	2.3	Not applicable	2.3

Prior to treatment 98% of the patients report inability to undertake daily activities – 30% missing activities for the whole month and 21percent missing daily activities for 25-29 days. Another 30% report missing daily work for 1-4 days. This has however improved substantially post treatment

when a third report not missing a single day's activity, while 44% missed just a day's work. **Post treatment, about 26% of TB patients in the survey reported being able to perfectly undertake daily activities, while 65percent report improvement to some extent and only a few report worsening. The response to ability to work was similar.**

Another challenge is to work with married women since they report with TB at the last stage when it becomes critical and can no longer be handled at home. The women also have difficulty in accessing services because they are responsible for their house and do not take or get time to take rest and consult any one for treatment. Also, women are generally ignored by the men of the family, resulting in her presenting late at the service point. **Improvement has been noted as men realise the impact on family health and life of the debilitating effects of TB on a woman.**

6.3. Awareness

Awareness measures have been carried out by NGOs in Theni, such as distribution of leaflets, wall advertisements, training programmes and cultural programmes for the communities, which they consider have resulted in better awareness and better health seeking behavior for TB. Awareness measures have contributed to the evident reduction of stigma. However, the evaluation survey could not confirm the direct impact of these activities, which would require a more extensive perception survey across the population.

A woman asked what she listened to on the radio said a community programme giving information on malaria, TB etc, called *Antwardoni*, a community radio programme, which is produced by AID as an activity of the project with a specific budget line. Besides radio, which many respondents gave as their first source of information on TB and its symptoms, and street plays and the masked "*chou*" dance, which has spread popularly from the tribal Purilia district of Bengal, have been used to convey health messages and raise awareness, while sports/cultural events also help identify TB patients. Under different funding, AID has supported traditional *Dakkua* communicators to communicate malaria and TB messages. Mayurbhanj district in Odisha has a high prevalence of malaria, which results in lower immunity to TB and higher incidence. Generally, TB is lower in the remotest areas and some Panchayats are free of TB, but one quarrying village having the highest TB prevalence of 21% before the project now only has two cases. ANMs appointed from outside cannot communicate in local languages and fear living locally in Naxalite areas. The impact of Naxalite activity is to limit both supply-side and demand-side behaviours. **The DFID CSCF project has seen considerable success in a two-way connection of unconnected villages with government services, where previously access was minimal, yet mutual knowledge of the roles and responsibilities of all players in this network remains weak.** NGOs in Theni still considered themselves to be acting as the liaison point between the RNTCP and the communities. Although most of the Theni NGO partners under this project see an objective to be a catalyst for community demand on service providers, such that NGOs can withdraw leaving a functioning and sustainable state system meeting the needs of TB patients, one partner NGO (Mythri) expects to continue providing TB services in collaboration with the RNTCP.

About 56% of surveyed Odisha TB patients sought advice at the private hospital after having a persistent cough for more than two weeks; 21% sought a traditional healer and 25% took traditional medicine, although the majority of the respondents (91percent) said their community did not have its own treatment for TB. **93% of Odisha patient respondents (98% in Jharkhand and 79% of the control, with 98% in Theni) reported that TB is a curable disease, with an equal percentage reporting that through DOTS treatment it can be fully cured** (although in Theni, 25% felt that it could only be managed rather than cured by DOTS treatment, possibly reflecting awareness of higher levels there of MDR-TB, although RNTCP staff considered they faced a challenge with low community awareness of MDR), reflecting a very high level of

awareness with nine out of ten patients (97% in Theni) knowing the standard treatment regimen. All TB patients in Theni expressed confidence that the DOTS centre was the best place for treatment of TB. In Theni, evaluators observed that lack of nutritious food was one cause of non-compliance.

Most communities in Jharkhand/Odisha covered by ASHA (Accredited Social Health Activist) have 3-7 cases of TB. In one extreme case, there were as many as 17-18 patients, but such instances were rare. In general, there were an average of three ASHA and/or *Anganwadi* (AWW) workers per village. 98% of patients in Theni reported receiving home visits, although half of these visits were being made by NGO staff and most of the other half by a combination of NGO staff and ASHA or Village Health Nurse (VHN) (17%) or NGO staff and ANM (8.5%) or NGO staff and RNTCP staff (21%), suggesting a continued dependence on NGO resources. Two-thirds were aware of volunteers, many of whom are former patients themselves and others leaders of women's SHGs, who are working with TB patients in the community in Theni.

In Odisha/Jharkhand, where sputum collection was not part of pre-project practice, currently volunteers and ASHA collect sputum from the remote areas. Peer educators and volunteers from among the "primitive" tribes in forest areas work with their communities, meeting at the Friday markets. ASHA in Jharkhand/Odisha reported that awareness levels about TB varied from village to village. In about half of the villages, the awareness levels were very high, but in the other half, it was estimated to be as low as 30%. All reported that all the villagers knew that they could contact ASHA/AWW workers to get the necessary treatment, including testing and medicines for TB. In most cases the ASHA/AWW workers provided counselling and follow-up to the patients. Sometimes they even took them to the Primary Health Centre and get the adequate testing done. In a few cases, they even bore the expenses of the case.

Apart from one village, where some NGO staff and volunteers also visited the patients in their homes; in all the other cases, it was only the ASHA/AWW workers who did so. On an average, they visited a patient three times in a week in his/her house. However, the ASHA/AWW workers reported that about 50% of them had received zero days of training in dealing with TB prevention and treatment. Even the ones who have received some training, it was rarely for more than two days. Only about half of the workers had attended a lecture/seminar/workshop on TB in the past year. **Despite this, the ASHA/AWW workers maintained that for all the reported TB cases in all the villages (except one) – they were able to maintain full treatment compliance, which has remained constant over the period between 2010 and 2013. However, the ASHA and *Angadwadi* workers appear unaware of the wider integrated framework to tackle TB.** Theni RNTCP staff considered that the role of VHNs and ANMs are not well integrated with the RNTCP programme and that this is a major challenge for them.

Evaluation interviews in Jharkhand/Odisha showed that health workers had the requisite awareness of the primary symptoms of TB and of secondary symptoms and knew of the tests that needed to be done to detect TB and that the treatment cycle was 5-6 months and was essentially curable through DOTS. Most of them considered worsening of symptoms and death to be the risk of an incomplete treatment cycle.

With regard to critical symptoms, 61% of Odisha respondents had awareness about cough for three weeks (94% in Theni); 35% about weight loss (10% in Theni); 23% about cough with blood (21% in Theni); with very few respondents reporting awareness of night sweat and diarrhoea (but 21% in Theni reporting wheezing as a symptom). Apart from these, other symptoms are mentioned by them, which are: vomiting blood, body ache, weakness, swollen glands, chest pain, loss of appetite, coughing & difficulty walking. In comparison, among control respondents, about 90% felt that TB is a serious disease and 45% reported cough greater than 3 weeks as a symptom of TB, 9.1 reported cough with blood, and 18% reporting fever as a symptom of TB.

61% of Odisha patients (46% of the control group) knew that TB can spread from one person to another and 54% (18% of the control) knew that open coughing and spitting spreads TB, whereas in Theni 82% affirmed this, suggesting a much stronger acceptance of medical evidence in Theni than in Jharkhand and Odissa.

83% of respondents in Theni were aware of the need for proper disposal of sputum, at least at the back or away from the house, with 60% stating that it needed to be collected in a container before being so disposed, while one-third considered that spitting outside the house or in a drain was safe.

61% of Odisha patients first heard of TB from the health facility or ASHA at the time of diagnosis, showing that more public awareness is needed to ensure better prevention and early treatment. With 12% first learning about TB from the radio, this has made a significant contribution to awareness. Only one person had heard that TB could be prevented by vaccine and none were aware in Theni that there is a vaccine that can prevent TB and can be given to children to protect them. By contrast, public awareness of TB in Theni is much lower, with 96% of patient respondents reporting having heard of TB only after the symptoms were developed and 85% citing government health facilities or ANM as the first source of information and a further 13% learning this from private health facilities.

6.4. Community Empowerment

Despite improvements in RNTCP functionality and reach among marginal communities in all three Districts, the evaluation team cannot be confident that community structures of VHSC/GKS and PRIs or tribal self-governing bodies, supported by self-help groups, are strong enough with sufficient capacity and experience, without continued NGO support in the background, to ensure that RNTCP continues to deliver and improve the quality and reliability of its services. However, **in Jharkhand/Odisha the practice of community referrals was hardly evident at the beginning of the project, but now 80% of referrals are by the community, with only 20% referrals made by project staff**, according to data for the month of December 2013. This suggests sustainable elements of community ownership and initiative in referring TB patients and helping TB patients to access TB services and caring for them. The support provided to TB patients, such as cash support from the untied fund and help from panchayats and youth forums are other evidences of community structures owning and responding to TB. On the other hand, the evaluation team found that PRI members in Theni revealed lack of awareness of their role in TB prevention and treatment. There are examples of VHSC success, but it is not systematic. One Theni VHSC in the evaluation took up advocacy for the appointment of a village health nurse and media advocacy with a TV channel to highlight health issues of the community. **Community awareness of TB is good, but knowledge of how to integrate this concern into the formal top-down RNTCP may require a more responsive and less centralised government system**.

Over 80% of TB patients in Theni were “very confident” and satisfied that staff in the local health centre would treat them appropriately and sensitively, although their household members showed a lower degree of confidence, with only 25% expressing confidence in the sensitivity of the ANM and VHN. With regard to seeking to improve services, over 60% would be ready to do this through the PHC and nearly 80% through an NGO or CSO, but only one in seven would look to the village Panchayat to do so, suggesting a continuing dependence on NGO advocacy. Patients remain on the margins of community activity, with only 10% belonging to any community organization.

AID has successfully advocated, backed by sustainable community lobbying and use of resources controlled by Village Health Committees, for improved services and support to TB patients, with some positive response from the government RNTCP. ASHA have become proactive in project villages and the majority of the patients now either consults with the ASHA or

else takes help from them. **In some locations, ASHA personally also help the patient and take them along to the hospital for treatment. The role of the ASHA and *Anganwadi* workers in the TB programme was found to be significant at service delivery and monitoring. The project facilitated the regularising of ASHA's honorarium, where previously the backlog used to be for 2 to 3 years, which has come down to 2-3 months.**

Village Health Sanitation and Nutrition Committees have been activated in the project intervention areas and have made the community aware about the Untied Fund and its utility. **According to the project staff, to date around 154 TB patients have benefitted from the untied fund ranging from Rs.500-Rs.2000 per patient. Primarily this money has been used for transportation of a patient for treatment. In many villages, the women's self-help group has also supported poor patients for their transport.**

6.5. Discrimination

Respondents were asked on discrimination faced at home and community. **Three quarters of the Odisha patient respondents report not facing any discrimination (contrasting with 58% in Jharkhand and 92% in Theni),** while about a quarter (33% in Jharkhand) report facing discrimination at home – not being allowed to touch others' cloth or utensils. Typically, the majority of patients (75percent) report not being allowed to touch cloths and utensils at 'home neighbourhood' and 21% report only at home. Otherwise one or two respondents reported living separately and managing alone. As regards current discrimination, only 7% report facing it at home and 2% at home and neighbourhood with the remaining 88% reporting no discrimination.

Have you personally in the past (in Odisha) faced discrimination at your home/neighbourhood /community (in percent)	
Never at Home, neighbourhood and community	74%
Yes, only at home	23.3%
Not applicable	2.3%

and

The survey data from Jharkhand/Odisha shows that the body the respondents had most faith in was the primary health care centre, followed by the village health committees. There was very high lack of awareness amongst the respondents about the Block Panchayat samiti and District administration's efforts. A similar picture emerges when respondents were asked about which organisations or individuals would they turn to improve services to their household members. Everyone unanimously mentioned the ASHA workers. ANM, health volunteers and primary health centres rank the highest.

6.6. Service Provision Improvements

According to AID, if a TB patient is the sole earner for the family, then he/she becomes reluctant to go for treatment as it results in loss of wages. In such cases, in some of the villages, VHSC have helped in covering the transport cost and loss of wages. According to project staff, to date 114 patients have been helped by VHSC spending Rs 92,000 (an average of Rs 807 or about £8 per patient). The Government of Odisha has a scheme, which provides a tokenistic amount of Rs. 250/- to each cured patient who takes DOTS treatment and whose compliance is perfect, which encourages the patient to take medicine regularly. For the first time in the history of RNTCP, more than 100 tribal TB patients benefitted from the health assistance scheme of the Welfare Department of the district administration **in West Singhbhum, in which TB patients got an entitlement of Rs.1000 each, which is a pacesetting contribution made by the project and it could happen only due to regular advocacy with the government by AID.**

Before the project, sputum tests were not available for the poor, so that family members were frequently infected with TB. **Now that the people are aware and there are means to get the sputum tested, family infection with TB has reduced significantly. The issue of sputum collection, transporting for test, providing medicine and monitoring of patients has now**

been mainstreamed through the ASHA, which has regularised compliance system even in the remote locations. For example, Brahmangaon Panchayat in Bangripasi block, which is remotely located, now has accessibility to TB services regularly through the ASHA. Before the project, there was a big challenge for sputum collection and transporting to the health centre.

Throughout the project period, TB treatment drug supply has not been a problem in Odisha, except for three months when an injection was not in supply. **In Odisha, there was streptomycin stock out in September and October 2012, following which the government ensured the supply of streptomycin after AID had highlighted the drug stock-out problem in a workshop with the government in the state capital, Bhubaneswar.** The State RNTCP acknowledged the disruptions in the supply of streptomycin and ensured the supply immediately - a good sign of pro-active and open governance in terms of TB drug supply. However, AID has reported problems with drug supply in Jharkhand and evidence of occasional reduced supply and stocks, including running out of streptomycin and child TB drugs stocks, indicating failure of the RNTCP and State health system. AID has recorded case studies of the impact of failure to supply a patient with a regular course of 24 streptomycin injections over the initial 2 months catgory-2 treatment, compounded by the cost of the drug at Rs12 each and of the injections at Rs5-10 each, for which ASHA, backed by AID staff, have asked the VHSC to cover from their untied funds. The child TB drug supply in West Singhbhum was disrupted in June and July 2013 before being restored, but in times of non-supply of child TB drugs, the Senior Treatment Laboratory Supervisor (STLS) instructed ASHA to break the adult TB drugs into equal halves, which is not ideal. AID has been successfully advocating with the various State and District health and RNTCP officials to ensure regular supply and for ANMs to fulfil their responsibilities to provide injections for category-2 patients and for national RNTCP protocols to be observed. **To sustain this will require greater accountability, through community led demand for RNTCP guidelines to be observed and failures addressed while reverting to local solutions through use of untied funds**. Theni found only one person who reported experiencing a drug stock-out in an earlier year and the NGOs reported that networking with RNTCP has resulted in this uninterrupted drugs supply.

Before the project, the Tribal Action Plan of RNTCP had become a dead document in Jharkhand and Odisha. **The project sensitised the State TB Officer (STO) and State RNTCP about the need for tribal friendly intervention and actual situation of specific problems of tribes. This spurred the State RNTCP to launch a state-specific RNTCP Tribal Action plan for the first time, which is now under implementation in 12 Scheduled Districts of Jharkhand**. Thus, the ripples created by the project made larger differences in terms of extension of tribal specific TB services in the tribal areas of the project, which is a significant milestone and achievement in the history of RNTCP. The Director of AID is the thematic lead for the TB Advocacy Group at the national level and has played a national role in shaping up the advocacy agenda of civil society. Several times tribal based experiences have been shared at the national and international platforms on TB, drawing this to the attention of the wider Indian civil society.

RNTCP is highly dependent on the quality and commitment of staff appointed, particularly the District TB Officer (DTO), who is in a position to ensure that subordinate staff perform. Theni RNTCP staff reported a lack of sufficient STS (Senior Treatment Supervisors) to cover the area. Some RNTCP staff had a reputation for not fulfilling their roles and only working for 2 hours in a day. One ASHA reported that some doctors sent patients to their own private clinic for treatment in order to earn money. A lab technician was known to ask field workers to send fewer patients fearing that testing a lot of sputum might infect him with TB. However, now the number of patients has increased to 60-70 visiting the hospital in a day and the community is very positive on health department's attitude as in every village people proactively talk well about the doctor and staff of the hospital.

Support for the VHSCs has contributed to increasing the demand for RNTCP services to be delivered in these poorly served districts according to RNTCP national guidelines and in Jharkhand led to the RNTCP-Jharkhand Tribal Action Plan which began to be implemented from April 2012 with the objectives to: encourage tribal populations to report early in the course of illness for diagnosis; enhance treatment outcomes amongst tribal populations; and promote close supervision of tribal areas by RNTCP staff. The Tribal Action Plan encourages and supports staff to reach tribal areas and that staff vacancies at the PHC level in these areas be filled, providing a salary supplement of Rs1,000 and maintenance allowance for two-wheelers up to Rs30,000 per annum, with support for patient/attendant travel up to Rs250, among other interventions[8]. The VHSCs have been important in expecting staff at PHC level to provide services as per the RNTCP guidelines and they have also been effective in promoting community level initiatives. However, three-quarters of respondents in Theni remained unaware of the VHSCs and it appears that it is NGOs that have led in networking with RNTCP, identifying suspected TB cases and sending these for testing and providing follow-up that has reduced the default rate. RNTCP staff in Theni also recognise the importance of their collaboration with NGOs in outreach, treatment, follow-up and monitoring, but acknowledge that they find it challenging to reach out to the middle classes, where NGO involvement is less.

Demand for services is still largely expressed by NGOs. For example, their advocacy for district level ART centres for treating AIDS in Theni has resulted in a better quality of service for co-infected TB patients. **Testing for HIV of those diagnosed with TB in Theni has steadily risen year on year over the project period from 82% in 2010 to over 98% in 2013.** NGOs have had **considerable success in promoting volunteers**, with many in Theni coming from women's self help groups and their federations, as well as former patients. Mythri, a partner in Theni, trains the volunteers on Tuberculosis awareness, referral services, drug monitoring and counseling. The volunteers give awareness to the community and refer suspected cases for testing. They carry out follow up and drug adherence monitoring. They also give counseling to patients on nutrition and to give up smoking and drinking while taking DOTS. The latest training was on Multiple Drug Resistance (MDR). However, these volunteers have not been paid their small honorariums regularly (only 3 out of 13 interviewed) and do not appear to be officially part of the RNTCP system in Theni. On the other hand, RNTCP in Tamil Nadu (Theni) has been paying Rs 1,000 as an incentive to patients for compliance, but a change in Government resulted in a different identification card as an eligibility criteria and many could not access the initiative. Dependency on NGO activity remains in the sustained effectiveness and reach of TB service in Theni.

[8] RNTCP-Jharkhand Tribal Action Plan (2012-13), published by State TB Cell, Jharkhand

6.7. Jharkhand/Odisha results in TB detection and cure:

Key Results planned	*Target*	*Baseline status*	*Achievement*	*Remark/justification*
TB death rate reduction	50% Reduction in deaths	8%	4%	50% reduction achieved in TB deaths
Failure to follow up rate (discontinuation rate)	50% Reduction in TB discontinuation rate	Baseline data showed that failure to follow up is more than 10%	3.68%	65% has been achieved.
Case detection	25% increase in case detection	90 -130/100,000 population per year	205 cases per 100,000 population in a year. The project achieved 100% more than the target.	The project exceeded the target.
Cured rate	95% cured rate	80-85% cure rate	92% cure rate till the end of December 2013.	Expected to achieve 95% by March 2014.
Source: AID (file name: Key Outcome Data)				

7. Logframe Indicators

There are problems with the design of the final revised Logframe indicators. The denominators for percentages are rarely defined. Account was not taken of the effect on indicators of increased identification of TB cases in the early years leading to higher than expected death rates until the backlog was cleared of previously undetected cases coming under treatment. Access and participation are not defined. The result is that indicators do not consistently fulfill all the characteristics of being SMART, although **the projects in the two areas do set out to achieve ambitious outputs and have had significant success in raising awareness and moving to early diagnosis of TB and to treatment compliance reducing the TB disease burden among poor and marginalized communities.**

8. Empowered target groups and Project Accountability:

In Jharkhand and Odisha, the project has continued to support AID's long-standing work of empowering local tribal (Adivasi) communities, especially those described by government as "most primitive", in the remote border districts where Naxalite activity has been the greatest over the past 30 or so years. This has included recruiting local Adivasi staff as field workers and coordinators for the project and supporting the establishment of VHSCs and their integration with Panchayati Raj and local self-governance institutions. The latter integration has not yet become fully effective where these community governance institutions do not see their role as being responsible for health services. AID has facilitated articulation of community demand for improved and sustained health service provision, particularly for TB patients, but communities have not yet presented their own coherent demand-side agenda that is not dependent on AID for

representation. **At community level, there has been major success over the project period in moving communities from making virtually no referrals to making 80% of the referrals of new TB patients.** AID's close working with community structures has enabled it to be accountable, evident from the way in which AID can leave these local structures to negotiate on its behalf with Naxalite cadres and leaders for the work to continue without hindrance or demands for "rent".

In Theni, the six partner NGOs have generally had a service delivery mandate rather than a broader empowerment agenda, except for AA and others working with marginalized groups such as PLWHA and transgender and sex worker groups, and work women's self help groups. There has been good use of former TB patients and of leaders of the women's SHGs working as volunteers with current TB patients. However, there has been no empowerment of TB patients such that they could form a group whereby they can corporately make demands on service providers. This may be due, in part, to the success of the project in creating awareness of TB as a curable disease in the medium term. Individuals are not therefore defined for life by their contracting TB and may not wish to be labeled permanently as TB patients through group identity – showing initial reluctance in the large evaluation meeting in so identifying themselves. However their willingness to commit a full day and the travel time to attend such a meeting and express their views in a working group and in plenary showed that they do see that they have a right to make demands for improvements.

9. Value for money (VfM):

9.1. Effectiveness

By focusing on the demand side for TB service provider behaviour change, access has increased. As new patients, displaying basic symptoms of TB, become aware of the prognosis of the disease with and without DOTS treatment and see that diagnostic and treatment services are relatively easily available from their local PHC with lower out-of-pocket cost than ineffective local alternatives, then more seek treatment. With increased public awareness, TB detection rates increase and a virtuous cycle begins of increased detection, higher treatment compliance, reduced MDR-TB, Category 2 and Extra-pulmonary cases, leading to lower spread of TB and higher cure rates with patients returning to normal productive life. The two keys to this outcome are firstly increased public awareness and demand for services and secondly a government RNTCP service that responds, particularly for those communities with higher prevalence and high risk of transmission due to labour migration into crowded urban and work environments, such as brick-kilns, factories and quarries. These are typical characteristics of those living in Theni and the tribal areas of Jharkhand and Odisha. **The evaluation considers that there is strong evidence that the improved RNTCP response is a result of increased articulation of demand from the community and to meet improved health seeking behaviour by those infected with TB who now know where to find diagnosis and treatment and the consequences of non-compliance.**

9.2. Efficiency

The project has been efficiently run with UK overheads at 7.9% of total expenditure and final project expenditure likely to be about 2% below budget. Overseas administration, including local transport, at 10.5% and capital costs (essentially 9 motorbikes, 15 bicycles, 3 computers, 2 digital cameras and multimedia equipment) at 2.6% represent cost-efficient overheads. The three major outputs have been delivered through effective staff teams (42.7% of overall expenditure) delivering capacity building at 7.6% and a range of awareness raising and influencing activities with production and dissemination of information, including through radio, hoardings & wall/rock paintings, community *mela* and World TB Day public events and workshops at 16.9% of overall expenditure. The success of Output 2, largely a government RNTCP response to the increase in

public demand and awareness of RNTCP service protocols, is evidence of the effectiveness of Outputs 1 and 3, where much of the staff activity and expenditure has been directed, apart from a small element of staff field support for patient compliance. The purpose of the project was not to provide direct services, but to bring a government health service response to effective awareness and service demand that leads to reduction in TB prevalence and impact. Overall, monitoring and evaluation has taken 7.4% of expenditure, but this has provided the evidence base for influencing, directly contributing to programme Outputs. The small UK public awareness work has cost 4.5% of overall expenditure. Although this small programme has not been evaluated, it is possible that **this UK public awareness expenditure might have been better targeted at UK corporate social responsibility potential for creating private sector support for sustaining the programme, given its efficiency and effectiveness, and influencing UK public opinion through the power of corporate sector messaging**.

9.3. Economy

In India, a course of standard TB drugs costs approximately Rs.1,000 (i.e. $17), MDR-TB drugs can cost more than Rs.100,000 (i.e. $1,700)[9]. The average cost for TB care globally is about $40[10], although no figure is offered by the Stop TB Partnership for MDR-TB care. As comparators, the World TB Day 2014 brochure gives the costs of TB care in Myanmar (South Africa) as $170 ($600) vs. MDR-TB care of $8,000 ($10,000)[11]. The same brochure estimates the infection rate from an untreated patient as up to 10 persons per year, which suggests the compound effect of non-treatment. In comparison to other countries, prevention of MDR-TB has a higher cost-benefit in India for the national RNTCP programme[12].

Even with a conservative assumption of only 3 persons infected per year by an untreated TB patient, the return on DFID investing Rs 7,270 through the Target TB programme **now** to reach one poor person with TB in a remote area is: (a) **saving in future treatment costs averted** of **Rs 2,362,446**; (b) **life-time earnings preserved for 30 children over 40 years and for 90 adults over 20 years = Rs 2,170,000; (c) saving by households on useless alternative treatment due to lack of knowledge of free diagnosis and treatment at PHC = Rs302,500**. Clearly children's lifetime earnings, if not removed from school due to sickness, could be much higher than current casual labour wages.

So the total return for investing Rs 7,270 now in Target TB and partners is Rs 4,834,946 (for Government Rs 2,362,446 and for the individuals Rs 2,472,500) over 20 years, assuming no continued exponential pattern of epidemic infections, or Rs 2,706,706 over just 4 years. **The return to investment is 38% p.a. over 20 years. Arguably, in terms of preventing an epidemic of TB spreading through migrant labour routes, investment in these poor marginal under-served areas has the greater returns. From a sheer economic assessment, quite apart from the question of the right to health, this programme makes eminent sense.**

---

[9] See Dr Sarman Singh, Faculty-in-Charge of Microbiology at AIIMS, New Delhi, writing in The Hindu on 6th July 2012 "Breathing Uneasy over TB": http://www.thehindu.com/todays-paper/tp-opinion/breathing-uneasy-over-tb/article3607912.ece accessed on 27 March 2014

[10] According to Dr Lucica Ditiu, Executive Secretary of the Stop TB Partnership, Statement in Johannesburg on World TB Day 24 March 2014. See http://www.stoptb.org/news/stories/2014/ns14_017.asp accessed 27 March 2014.

[11] See page 9 of the brochure, which can be downloaded from http://www.who.int/campaigns/tb-day/2014/campaign-brochure/en/. Accessed 27 March 2014. See also the India Ministry of Health & Family Welfare RNTCP assertion of the same risk of infection of 10 persons per year: http://www.tbcindia.nic.in/rntcp.html accessed 1 April 2014

[12] The Evaluation Team has not been able to confirm if this is due to basic TB drugs being available from Indian sources while the specialist MDR-TB drugs are imported at high cost.

10. Innovation

The use of volunteers, many former TB patients themselves and others from women's self-help groups, to support treatment compliance has a positive effect in Theni where it is a strong element of the programme, having greater impact on patient behaviour than working through the Village Health & Sanitation Committees to raise awareness of TB and support individual treatment. Local volunteers have also proved effective in Odisha/Jharkhand tribal areas due to being indigenous and understanding the local culture and language, working with communities through the Friday markets. In addition to use of radio and sporting events, messages are put out through the masked "*chou*" dance from the local tribal region of Bengal. On the other hand, the VHSCs have proven valuable in enhancing provider behaviour and service accountability.

11. Sustainability

In Theni, the project has resulted in efficient engagement with CSOs in implementation of TB prevention and control. It is evident that NGOs, Women's Federation and Self Help Groups are actively engaged in identification, referral, and drug monitoring. However, their engagement in advocacy for policy formulation is not so evident. **The project has a clear strategy for sustainability, for example, the NGOs have constantly engaged in capacity building of the staff, DOTS volunteers, women leaders from federation and self help groups. While there is the potential for work being continued after the graduation of the project, the community level institutions have failed to be integrated into the RNTCP system**.

The state level network called 'Tamilnadu Tuberculosis Control Network' has been launched in February 2014 with the objective of better awareness, better services, and zero death due to TB. This network is expected to influence policy changes but it would take considerable time and capacity building to enable the patients themselves to take part in such networks and be part of the advocacy process.

12. Realisation of Risks

AID has a clear security policy for working in the insecure Naxalite environment, which recognises that the best way to defuse any crisis emerging from ultra-left outfits is through a community-led approach, including community, not AID, led negotiation if needed, and using volunteers and field staff from the local area, accompanying any driver or visitor. AID uses risk assessments and mapping of risk areas, with regular monitoring of media reports and local information with a mobile phone reporting mechanism, avoiding field visits on days for which a Naxalite bandh has been organised and addresses safety and insurance aspects, with orientation and induction training. AID staff are highly diverse in social and religious backgrounds, with a recruitment preference in all appointments for local Adivasis, enabling them to be sensitive to a range of cultural and religious issues.

With regard to drug stock-outs, putting the whole treatment programme at risk, both projects have used a range of District, state and national advocacy, backed by local communities and CSOs, that has led to sustainable drug supplies. The same combination has been used to ensure that grants are made from untied funds for patients transport or similar needs and incentives for compliance are met.

13. Contribution to CSCF Objectives

See Annexe A

14. Contribution to the Millennium Development Goals

This project contributes to MDG 6 – to reverse the incidence of TB by 2015 – through achieving equity of access to TB health services in India, particularly for poor and marginalised communities and by achieving increased detection of TB and significant reductions in mortality and MDR-TB prevalence and significant reductions in TB prevalence in marginal communities who are active in labour migration and therefore present a public health risk.

15. Lesson Learning

15.1. Approaches to Empowerment and Advocacy

Working with the institutions of local governance, which are weak in such marginal areas, is a slow process and leaves a tension between achieving more rapid changed health outcomes through NGO implementation and advocacy or slower, but more sustainable, community demand for government service delivery improvements. Given the public health gains in the short term, there could be a case for a less sustainable approach. However, use of community radio in Jharkhand/Odisha has not only empowered tribal groups, but also delivered changed knowledge and practice and increased positive health seeking behaviour with regard to TB diagnosis and treatment. **Once local self-governance institutions and village health committees and community based organizations, particularly women's SHGs, are integrated into the health structures, including RNTCP, then public health will rise up the agenda of both communities and state and a virtuous circle of demand and supply improvements will occur.** Until then, sustaining quality of service delivery will be dependent on NGO advocacy and remain dependent on individual staff and postings.

15.2. Equity

AID's recruitment of local Adivasi staff, men and women, to work as field staff and coordinators for their own communities increases influence for health-seeking behaviour change, but also reduces security risks in a conflict area. The projects in both Theni and Jharkhand/Odisha have supported women's SHGs and the village health committees and have enabled stronger links to develop between these and the PRI structures, enabling women in particular to be heard as a result of this institutional strengthening. In Theni, this has included working with PLWHA, sex worker and transgender groups, all of which would otherwise be marginalized by the wider society and as a result these experience lower levels of discrimination and are willing to engage in public meetings, including the initial evaluation meeting. In Jharkhand/Odisha, **sensitization of men, including tribal elders, young people, male partners/husbands and male volunteers on the importance of women's health and its impact on the whole family has led to support for women seeking treatment earlier, with men often accompanying them to the local PHC and caring for them at home.**

15.3. Capacity building

Both the Theni and the Jharkhand/Odisha projects have invested heavily in training over the four years (e.g. 2175 women and 2655 men in Jharkhand/Odisha from nearly 400 self-governing or panchayat institutions, over 200 youth clubs, nearly 400 women's SHGs and over 1,000 from cultural and sports forums and volunteers) and engaged with around 300 ASHA and 300 Anganwadi workers. However, capacity building is not only about delivering training from a formal health perspective, but requires listening and endorsing positive local values. In Jharkhand/Odisha, the project has taken a tribal community-centred approach in engaging with

the traditional self-governing structures – the Manki-Munda system of the Ho tribes and the Manji-Pradan system of the Santhal tribes – which has created legitimacy for project approaches to addressing TB. This has resulted in community support for TB patient care and removed myths and misconceptions around TB and its causes and effects. It has also overcome language barriers and the fear of exploitation by outsiders, removing many of the community barriers against health/TB services in these tribal areas. **In contrast to the top-down health service model, the tribal community-centric and inclusive, equitable and non-discriminatory, approach is seen as more patient friendly and non-threatening to TB patients. It has helped bring in to the TB treatment programme the local health service providers – the *Sahaiya*/ASHA, Anganwadi Workers and ANM – who are trusted by the community.**

15.4. Monitoring & Evaluation

AA has contracted out monitoring to the Pune-based Maharashtra Association for Anthropological Studies (MAAS). MAAS carries out an annual survey, which informs programme approaches. The six partner NGOs in Theni operate a common computerized data system, but this is based on a manual patient data record system shared with the government RNTCP patient data that records all patients and their treatment and outcomes. Both the projects in Theni and in Jharkhand/Odisha will be completing final data against the baseline and MAAS will present an update for their annual survey after project completion, since these are part of the ongoing programme monitoring involving other projects. This independent evaluation does not repeat what will be entered by Target Tuberculosis in its Project Completion Report (PCR). **The data generated by this independent evaluation has served to confirm the validity of the data that the projects submit annually.**

16. Recommendations

- **More substantial epidemiological research** that can compare TB incidence over time, location, identity and its correlation with malaria, HIV etc. – in Theni there is co-infection of 10% (530 out of 5,242) TB patients with HIV (10 out of 32 death case studies were co-infected patients whose CD4 count had gone down), whereas in Jharkhand/Odisha, where in only one block has male migration a decade earlier to a port city in Gujarat led to higher HIV, there have been no TB patients co-infected with HIV, but malaria prevalence is thought to make people more susceptible to TB. This epidemiological research could complement the results of a GFATM-funded WHO/GoI national study due to be published in July 2014, based on 100 districts across India showing the overall TB prevalence of 203/100,000 in 2003/04 falling to 165/100,000 in 2013, subject to confirmation. This could be linked to use of digital mapping of key morbidity distributions and service provision and performance that can be continuously updated through simple mobile phone technology. It could also look at the degree of drug treatment side effects in patient non-compliance and also that of the non-affordability of adequate nutritious food.

- **A radio listener survey** linked to Knowledge and Practice assessment and identification of programme formats and content that are effective in increasing referral of those with TB symptoms to PHCs, which could confirm the degree to which radio has become a voice for the marginalised and effective in changing knowledge and practice from within the cultural ambience. Impact of such IEC should be assessed against use of traditional music, poetry, dance and drama. The potential for extending cellphone functions to mobile banking and as a radio platform would increase remote villager connectivity.

- **Death registers**, currently not well kept by government especially in Naxalite areas where staff could be criticised by the DMO for lack of action, to be maintained by Village Health Committees and the local ASHA **leading to a system of TB death audits**.

- **Increase the role of multi-purpose health workers** as part of health committees or Panchayats to provide treated bed-nets, sprays etc for malaria and with Panchayat support to help TB patients access BPL/destitute rice distribution schemes, NREGA employment access and pensions, while the village *Angadwadi* workers could help extend ICDS nutrition for those with TB. ASHA and *Angadwadi* workers need to be brought to the centre of the state and district RNTCP programmes as key programme implementers and publicly recognised for their role and achievements.

- **Small incentives for treatment compliance** for patients and staff can have high returns on the investment. The Jharkhand RNTCP Tribal Action Plan use of incentives for staff who are willing to serve in remote areas shows how incentives, rather than simply information and skills as outlined in the Target TB Theory of Change, are needed to change the pattern and quality of service delivery.

- RNTCP should **evaluate the cost-benefit of immunising** with BCG the children in households of a current TB patient to give a certain degree of protection against intra-household transmission.

- There appears to be a gap in knowledge and awareness of services available at the PHC level and the structure of the RNTCP service up to District level. A more conscious effort is needed to **ensure that communication is improved between the district RNTCP staff and the village level health workers** so that they become part of an overall service delivery and TB monitoring team.

- NGOs need to continue their support for building the capacity of Village Health and Sanitation Committees and community awareness of their role and of other community self-help groups in order to sustain the demand for quality services that reach all remote and marginalised communities. **The role of volunteers should be integrated into the state RNTCP programme and agreements made on payment of small honorariums**.

- Influencing UK public opinion is important for accountability of DFID-funded work and to maintain public commitment to effective development programmes, but this would be more effectively channelled through **private sector companies and their corporate social responsibility, which in turn can generate resources for continued programme reach and influence the public**.

17. Annexes (Annexe A: Achievement Rating Scale; Annexe B: Return to Investment)

17.1. Logframes; Evaluation ToR & Plan; Declaration;

18. Annexe B: Return to Investment

Assumptions based on WHO, RNTCP and Evaluation evidence[13] , with calculations in Indian Rupees

Project Costs per TB patient[14]	7,270	
Matching RNTCP costs per patient	9,038	
Drugs (DOTS) per TB patient	1,000	
Drugs per MDR TB patient	100,000	
Project & RNTCP Costs of Treating one TB patient NOW		**17,308**

Costs of treatment delayed by 4 years
(leading to 120 (3+9+27+81) additional TB patients over 4 years with 4 (1+3) dead; 36 unable to work; 12 with MDR-TB; 30 child patients)[15]

Loss of earnings over 4 years:		
1 x 4yrs x Rs720	2,880	
3 x 3yrs x Rs720	6,480	
9 x 2yrs x Rs720	12,960	
27 x 1yr x Rs720	19,440	
4yr earnings loss		41,760
Loss of lifetime earnings:		
90 adults x 20yrs x Rs720	1,306,000	
30 child x 40yrs x Rs720	864,000	
Lifetime earnings loss		**2,170,000**
Costs out-of-pocket of Ineffective Alternative Treatments[16]:		
121 patients x Rs2,500	302,500	
Loss of wasted treatment costs		**302,500**

Saving in RNTCP future treatment costs for 117 diagnosed with TB, excluding those already dead:

Staff costs: 117 x Rs9,038	1,057,446	
DOTS drugs: 105 x Rs1,000	105,000	
MDR drugs: 12 x Rs100,000	1,200,000	
RNTCP Treatment costs averted		**2,362,446**
Lifetime earnings preserved		**2,170,000**
Wasted out-of-pocket treatment costs		**302,500**

[13] The calculations have been based on conservative assumptions. For every untreated TB patient, particularly poor migrant workers, assuming (i) an infection rate of 3 persons per year (conservatively less than the WHO estimate of up to 10 persons); (ii) inability to work after 3 years due to death or progressive deterioration; (iii) 10% of untreated patients developing MDR-TB. After 4 years the disease burden will be 4 persons totally incapacitated or dead; 36 unable to work, including 4 with MDR-TB and 9 children; and 81 newly infected, including 8 with MDR-TB and 20 children, and a total of 117 with TB, excluding the 4 incapacitated/dead. Further assume in line with the data gathered in the evaluation: (iv) a daily labour wage of Rs50-70, say Rs60; (v) 15-20 days per month unable to work on average for everyone with TB during their initial 3 years and totally unable to work after 3 years untreated; (vi) 80% of treated TB patients able to work 75% of the time over an average 20 years further working life; (vii) staffing and programme costs reaching 6592 TB patients over the four-year project life, costing £72.70 (Rs7,270) per capita; RNTCP staffing costs at Rs9,038 ($300m for 1.8million diagnosed annually according to http://www.tbcindia.nic.in/rntcp.html); and drugs cost of Rs1,000 (Rs 100,000 for MDR-TB drugs). Using $1 = Rs60.23 and £1 = Rs100.

[14] Based on overall CSCF 502 project costs of £479,223 serving 6592 patients

[15] Assuming only 3, rather than WHO estimate of 10, infected per year with 25% being children and 10% having MDR-TB

[16] Assuming patients continued to be ignorant of TB symptoms, free diagnosis and treatment, pre-project treatments costs prior to diagnosis were Rs2,500 (footnote 2, above) and those in the evaluation survey, not including those who went straight to the PHC, paid a mean of Rs5,000 and a median of Rs2,500 before PHC diagnosis.

20 year return on Project Investment of Rs7,270 (split roughly equally between government and poor households)	**4,834,946**	**or 38%p.a.**
4 year return on Rs7,270	2,706,706	