Tribal populations constitute a special challenge for India’s health services. They remain outside the purview of development as they are often migrant or residing in geographically remote and inaccessible areas, with little or no access to the state’s education and health systems. Given their historically distinct lifestyles and belief systems which are increasingly at odds with India’s rapid urbanisation, poverty too is now almost endemic in these communities.

Both poverty and a lack of infrastructure have long presented hurdles to the efforts of the RNTCP in reaching out to this complex and vulnerable demographic. For the national programme as well as civil society, creating awareness and delivering health services to these communities remains a challenge and a priority for improved TB control.

In this edition of the newsletter, we showcase experiences of partners across the country working in tribal areas to reach these marginalised populations and bring them access to TB services. We introduce the Eli Lilly and Company (India) Pvt. Ltd. working to build India’s capacity to deal with, and lower, the burden of MDR-TB. We bring you stories of impact on vulnerable communities, with a focus on motivating the previously unreached to reach out for their services, rights, and entitlements.
Know Your Partner

Eli Lilly and Company (India) Pvt. Ltd.

How does the Lilly MDR-TB Partnership figure in the company’s CSR practice around the globe?

Tuberculosis (TB), often thought of as a disease of the past, continues to plague the world’s most vulnerable populations. The Stop TB Partnership estimates there are around 9 million new cases of TB globally each year and about 2 million deaths.

These dire statistics are even more dismal considering that TB and MDR-TB are treatable and curable. The real problem lies in the fact that TB - in all its forms - is a complex disease, one which is not only a medical problem; it is also a social and economic problem.

The Multiple Drug Resistant Tuberculosis (MDR-TB) program is Lilly’s marquee global access program and part of its commitment to corporate citizenship. Due to the complexity of MDR-TB treatment, Lilly developed a comprehensive strategy that included transferring Lilly drug-manufacturing know-how to pharmaceutical companies in countries that are hit hardest by MDR-TB; supplying drugs to the WHO at significantly reduced prices and implementing training and awareness programs with other partners in order to prevent & treat MDR-TB correctly. We were guided by experts in the field and were honored to have some of the international organisations like the WHO, PIH, ICN, WMA, IFRC, WEF as our partners and then we developed partnerships in our focus countries to help and guide us in our work.

Why does Lilly place its emphasis on partnerships when it comes to fighting tuberculosis in India?

The devastation of TB is a stark and inescapable reality for many individuals, families and communities around the globe. Lilly and its Partners work together, sharing knowledge, expertise and research in the quest to contain and conquer MDR-TB, a disease that disproportionately affects impoverished populations. The initiatives of The Lilly MDR-TB Partnership all have one thing in common: improved care for some of the world’s most vulnerable people, delivered in a manner that is sustainable and builds capacity within the communities where it is needed most. We have been able to train health care providers- doctors, nurses, program managers, pharmacists and rural health care providers. We have put in place innovative community based programs in place to support patients seek early case detection, community support and counselling for treatment completion and adherence.

Through the Partnership, Lilly aimed to create a sustainable source of capreomycin and cycloserine and to fund programs that would ensure proper diagnosis and treatment. Its goal was to increase the availability of capreomycin and cycloserine and by leverage government relationships to support effective policies. Lilly communications about the Partnership invoke the Chinese proverb: “Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime.”

As a corporate, what unique insight, skills and strengths does Eli Lilly bring to tuberculosis care and control in India and around the world? What is the role of corporate in disease control efforts and how might investment be increased in India?

Recognizing that MDR-TB cannot be halted by medicine alone, in 2003, Eli Lilly and Company officially created The Lilly MDR-TB Partnership. This public-private initiative now mobilizes over 25 partners on five continents to tackle the scourge of TB and MDR-TB head on. Lilly contributed US$ 120 million in cash, medicines, advocacy tools and technology to focus global resources on prevention, diagnosis and treatment of patients with MDR-TB; and an additional US$ 15 million to the Lilly TB Drug Discovery Initiative to accelerate the discovery of new drugs to treat TB. The company made this investment to ensure that thousands of MDR-TB patients receive the care and medication they need to combat this disease.

The Eli Lilly and Company Foundation will support the Partnership for five years (2012-2016) and will work with partners at the global and local level, with a specific focus on partners in the four countries carrying the highest burden of MDR-TB: China, India, Russia and South Africa. The two objectives of this partnership would be to work with Government and other stakeholders to increase access to quality assured drugs and build the capacity of health care providers.
Corporate Partners can contribute to this public health challenge by partnering with the Government and supporting the National Program in various ways – there are some examples where the corporates have put in place effective work place programs and have reached out to their employees and also to the communities they are operating in but the total contribution is albeit too small. More needs to be done to engage them in the National TB Program so that they can meaningfully contribute.

**What is the Lilly MDR-TB Partnership’s short- to medium-term view on MDR-TB in India? How are you working with the Indian government to curb the threat?**

Lilly MDR-TB partnership’s engagement with the Government TB Control Program and all its implementing partners has been very collaborative. We seek the advice of the Central TB Division and work with the State TB Department. We seek their guidance on the selection of the districts where programs can be implemented and also seek their support for evaluation and monitoring. To increase case detection and reach the goal of Universal access we need innovative approaches to supplement the regular initiatives. It is our endeavours to come out with tried and tested models and share it with the Program for its National Roll out. For instance we have provided counsellors at DOTS plus sites and their role in increasing adherence and reduce default has been well documented. We are working with several partners to build the capacity of Health Care Providers like the nurses, pharmacists / chemists, doctors, private providers, rural health care providers and community based volunteers.

TB and MDR-TB continues to be a blight amongst India’s most vulnerable populations partly because awareness is so low, however, there are initiatives like Project Axshya that are committed to raising the level of awareness across the country through civil society partnerships. Based on Lilly MDR-TB Partnership’s work and experience in other countries what other approaches does it recommend raising the levels of knowledge and awareness in India?

I believe that the work being done by Project Axshya is unique. It provides an opportunity to make a difference by raising awareness levels across the country in 300 plus districts. Civil society can be a vibrant engine of this effort to increase the levels of knowledge and awareness, we also need to use the youth power to generate awareness and utilise social media to reach out to the young people in our country.

### NEWS & EVENTS

#### Steering Committee Meeting

The 10th steering meeting of the working group was held on 04 December 2012 at Hotel Visaya, Panchsheel Park, New Delhi. Discussion points included preparation of sessions for the national consultative meeting to be held in January 2013, updates from meetings attended by members, and various other issues like membership and the theme for the next edition of the newsletter - stories from tribal/hard to reach areas.

Details available at [http://www.tbpartnershipindia.org/aboutcom.asp](http://www.tbpartnershipindia.org/aboutcom.asp)

#### 1st Forum of National Partnership in Korea

Dr. Nalini Krishnan (REACH), Dr. K. S. Sachdeva (CTD), Mr. Subrat Mohanty (The Union) and Dr. Darivianca Laloo (Secretariat) attended the first forum of National Partnerships held in Seoul, South Korea on 22 and 23 November 2012 to share experiences and also present their request for funding to national partnerships. This forum was organized by the Korea Stop TB Partnership and Stop TB Partnership Secretariat, Geneva. A work plan of prioritised action for the India partnership was submitted. Its two areas of focus were capacity building of partners to empower communities for TB care and control, and increasing the involvement of the private sector with the National TB Program.
World AIDS Day

Mamta Samajik Sanstha (MSS) reaches one million people during World AIDS Day 2012. Zero HIV infection, Zero discrimination with HIV positive persons and Zero death because of AIDS - these were the key messages of MSS AIDS Prevention Campaign launched on 29 November, 2012. This week long campaign was conducted under the leadership and guidance of Mr J.M. Singh, Chief, MSS with the support of MSS staff, district coordinators, and 72 NGO partners in 13 districts of Uttarakhand and 5 districts of western UP under Project Axshya.

MSS conducted this AIDS awareness drive in its 18 districts in UK and UP to sensitize marginalised and vulnerable populations, both in urban and rural areas, on TB and HIV with emphasis on reaching the unreached populations.

The major activities organised under this event included - mobile awareness rally and van, street play, TB-HIV awareness programmes for highway truckers followed by condom distribution, quiz competition in high schools and colleges, poster competition, slogan writing, poem writing, puppet show, a candle march, signature campaign and rickshaw rally. Participants came out to show their support of the red ribbon express stationed at Dehradun (Raiwala Station) and at Saharanpur stations, making it a truly participatory and memorable campaign.

Submitted by: Mamta Samajik Sanstha

“Rights and Entitlements of TB patients”

A state level workshop on “Rights and entitlements of TB patients” from tribal perspective was organised 12 December 2012 at Red Cross Bhavan, Bhubaneswar, by Alternative for India Development (AID-India), a national non-governmental organisation (NGO) working in Odisha, Jharkhand, Andhra Pradesh, Tamil Nadu and Pondicherry.

The purpose of the workshop was to highlight the key issues of concern on TB and to forge an alliance with civil society groups in support of the rights and entitlements of TB patients. The workshop had 37 participants, including researchers, activities, and officials from the Revised National TB Control Programme. It was inaugurated by Dr. Laxmidhar Pradhan, Medical Officer and Dr. Das Mohapatra, State Co-ordinator from State TB Cell in the presence of Dr. Satya R. Panigrahi, District TB Officer of Bhubaneswar.

Dr. K. T. Arasu, Director, AID-India made a presentation highlighting the following issues affecting TB services in the state.

- Delays and backlogs in disbursement of incentive amount for ASHAs and beneficiaries.
- Non implementation of Tribal Action Plan by Odisha state.
- Frequent change of DTOs and delay in filling the post.
- Lack of interest to fund NGOs for TB specific schemes of RNTCP
- Non-availability of category-II TB injection
- Lack of sufficient facilities for diagnosis of extra-pulmonary TB.

Dr. Panigrahi presented on the various facets of TB, a complex infection that can affect all parts of the human body excepting hair and nails. He also emphasized that “the district hospitals have the facility to detect extra-pulmonary TB, including TB for children.”

Dr. Das Mohapatra drew attention to the prevalence of TB co-infection among people living with HIV and the devastation caused to the patient through TB. He said “Opportunistic infections like TB are one of the leading causes of deaths among people living with HIV.”.

The workshop ended with a note to continuing work with commitment towards a society without TB and urging various TB authorities to initiate action on the issues highlighted.

Submitted by: AID India
SUCCESS STORIES

Reaching out to quarry workers in Karnataka

Population Services International (PSI) is currently implementing Project Axshya in 30 districts, including 5 districts of Karnataka, of which Haveri is one. The quarry workers at stone crushing sites in the district of Haveri form an important group in the vulnerable population demographic and often do not have access to information and services.

Mr. Uday Shankar (IPC co-ordinator) from PSI conducts interpersonal communication (IPC) sessions at the quarrying and crushing sites in Haveri. He reaches out to the workers at those sites as well as the drivers who are responsible for transportation of the crushed material. Initial mapping of these sites was followed by advocacy efforts with key persons at the respective quarrying sites to allow for such awareness sessions to be conducted. So far Mr. Uday Shankar, IPCC of Haveri has reached out to more than 200 quarry workers through individual group sessions.

An effective IPC tool that was developed after thorough research is used by the field staff to improve the self risk perception of individuals with a cough for more than two weeks. The objective is to sensitize these communities on symptoms of TB, and motivate such individuals to go to the nearest health facility for a diagnostic test.

Volunteers have been identified and trained to identify persons possibly suffering from TB and refer them to the nearest DMC for diagnosis. The nearest DMC from such site is around 12-15 kms and facilitation of sputum transport is required. The volunteers of those sites have identified and referred four TB suspects of which one was found to be positive for TB and was initiated on treatment.

This activity was initiated across three such sites. Presently the team in Karnataka led by Mr. K. Srikanth (State Program Manager) is focussing on developing a peer educator model for sustainability. The peer educator model is being replicated across other locations.

Submitted by: Population Services International

Reaching rural and tribal communities through NGO, CBO and RHCP partnerships

Project Axshya continues to make inroads in the field of community mobilization through its various Gaon Kalyan Samittee (GKS) or Village, Health, Nutrition and Sanitation Committee (VHNSC) meetings and midmedia activities. To date, approximately 5000 VHCS/GKS held at each district, and over a hundred thousand people have been made aware of TB prevention and treatment services.

Moreover, the project has reached previously unreached rural and scattered tribal communities through the involvement of local NGOs, CBOs & Rural Health Care Providers. A handholding strategy has built a great network between the rural community and service providers. Nearly 20 NGOs, 20 CBOs and 200 RHCPs have been trained in each district. They are all actively contributing to strengthen TB services in their various capacities - through referrals, sputum collection and transportation, and retrieval of patients who have discontinued treatment.

The Formation of District TB Forum is one of the best initiatives that has become an unique instrument for strengthening the district level programme and addressing the gaps between service providers and TB patients. Forum members take the initiative to monitor the programme and advocate for TB patients’ rights. They distribute and publicise the patient charter, organize meetings with district health authorities, submit memorandum to district collector and others, all the while advancing the rights of patients.


Submitted by: CBCI-CARD
Impacting the Community...

Jorhat Christian Medical Centre (JCMC) has been working in the remote villages of Jorhat district in upper Assam since 1924, touching and transforming lives of people especially by improving health and wellness through house visits, health talks and health camps. Its community sub-centre currently covers a total of 10 villages in the Jorhat district with a population of about 5,000 mostly tribal people belonging to different communities. Since these are interior villages, there are neither health facilities available nearby nor regular visits from any government health workers. It is therefore largely through the committed and sincere efforts of some health workers at the JCMC sub-centre that many people have come to know about the prevention, treatment and care of TB. They have also gone for sputum testing and treatment at the nearest health facility.

One such story is of Mr. Jacob Nag, aged 67 years residing in Tengajan village with his family. He had been suffering from an on and off fever with cough and deteriorating health for 2 years. He was prescribed paracetamol for this from nearby quacks. During home visit programme by JCMC staff, he was repeatedly advised to go for proper testing for TB at the nearest civil hospital. He was later diagnosed with pulmonary TB, and completed the full ATT course. Now that he is healthy and strong again and he has also resolved to tell his neighbours and friends not to ignore symptoms and shy away from proper testing for TB and to take proper treatment.

There are many more such cases where efforts at raising awareness about disease prevention translates into a huge impact in the lives of communities.

Submitted by: Jorhat Christian Medical Centre (JCMC)

Micro Effort: Macro Result, Lubengarh shows the way

In the map of India, Kalahandi may often be identified with drought and starvation, but recently the small Lubengarh village has been showing others the way forward.

Anyone wishing to reach this remote village from Panchayat headquarters Urladani (a tribal dominated Panchayat in M. Rampur Block), has to walk around 30 kms, crossing 3 rivers and hills enroute. People from Lubengarh used to walk this distance to reach panchayat headquarters and then travel around 16 kms depending on irregular transport service to reach nearest CHC at M. Rampur. Given this situation, most of the health services were well beyond the reach of the people there.

During a study conducted by Seba Jagat on immunization coverage, it was revealed that the immunization coverage in this hilly area is very low. A discussion with village youths revealed the need for a health and immunization camp at Lubengarh. Staff from Seba Jagat discussed this with Medical Officer of M. Rampur CHC, who was delighted to hear the plan for a health camp. It was finalised, and Seba Jagat spread the word to nearby villages, selected a suitable place and also informed the SHG, PRI, ASHA, AWW, and VDC members for their co-operation.

On 14 August 2012, the first Immunisation and health check up camp was organized at Lubengarh. Doctor, Pathologist, Pharmacist, LHV and other health personnel were present along with local ANM, ASHA and AWW. The result was tremendous. Beneficiaries from more than 10 village came for the service, and the camp was conducted consecutively for three months, from which more than 400 people benefited.

Jogeswar Majhi of Lubengarh village says very happily, “I cannot believe my eyes that there is such a big health camp in our village. Now I know the health service is there for us. All we have to do is to talk together and co-operate each other.” Following the success of the first, two camps were subsequently conducted in nearby villages. These three health camps are the beginning and a reminder that together we can take health services to people so that no one remains unreached.

Submitted by - Seba Jagat
Reaching the Unreached

MEERA FOUNDATION is an AXSHYA Partner with REACH (SR) in Dindigul District, Tamil Nadu conducting ACSM activities from 2011. The NGO is involved in outreach through small groups meetings and uses flash cards, flip charts and pictures on TB and treatment. MEERA has taken an interest in Childhood TB from 2012, and pledged to promote child nutrition during the treatment period with support of stakeholders and other groups. Towards this end, MEERA’s team visited a village Karuthanayakkampatty in Natham Block on 21 December 2012 and organized a meeting (GKS) with women self help group. Mr. Raja Mohamed, Director, MEERA FOUNDATION presented session on TB Symptoms, transmission, cure, available services, community role on TB control, TB-HIV co-infection and childhood TB. He facilitated discussions about TB and clarified many misconceptions.

One participant, Mrs Parameshwari, voiced her doubts about her daughter’s health. Her 7 year old daughter Sathyashree was being treated at a private clinic for TB for past three months, and the family had been suffering from the associated expenditure. Mr. Raja Mohamed motivated her to avail RNTCP services at the nearby PHC, three kilometres from her village. She didn’t prefer to go to the PHC as she had heard negative feedback on Government Health Services. He counselled the parents again, and convinced them to avail services provided by the RNTCP. MEERA Volunteer followed Sathyashree’s case since the child came for medical investigations at Natham GH, diagnosed, and started on treatment. Now, the parents are confident about RNTCP Services and they are well informed about TB Care and DOTS. This goes to show that proper and effective information or education is highly influential in making people seek health services at the right time and the right place.

Submitted by: MEERA Foundation

Anita as DOTS provider

In January 2011, Project Axshya began implementation in Jhabua District of Madhya Pradesh, with local implementing partner Adivasi Chetna Shikshan Seva Samit Jhabua supported by CBCI-CARD in New Delhi.

Mrs. Anita Pal is a community volunteer who was sensitized and trained about TB during local NGOs training program of Project Axshya CBCI-CARD. Now, she has been actively involved in Project Axshya activities, especially among tribal population, for two years. She helps the NGO in conducting GKS/VHSC meetings and other community sensitization programmes. Through the course of these meetings and field visits, Anita has referred 34 persons with symptoms of TB to the nearest DMC Thandla and DMC Meghnagar. Among these suspect cases, six persons have been diagnosed as sputum positive TB patient. Additionally, Anita has become DOTS provider for 3 of these TB patients, one of whom have already been cured through DOTS. Her services are proving indispensable to this rural community.

Submitted by: Adivasi Chetna Shikshan Seva Samit Jhabua

Rural Health Care Provider dedicated for referrals

Mr. Ranjeet Maurya, a young man of 30, comes from a family of farmers and Rural Health Care Providers in Soharsa village of district Faizabad. He came across Project Axshya during a Gaon Kalyan Samittee (GKS) meeting and through its mid-media programs in April 2012. On evincing interest in the activities, he was trained by MAMTA AXSHYA in July and has been involved with the project ever since.

RHCP Mr. Maurya has regularly been referring 3-4 persons showing symptoms of TB to the Rudhauli DMC every month. Of these, 6 people have been diagnosed with TB and are under DOTS treatment. NGO Ramawati Smarak Society specially gave the RHCP motivational support for these detections by facilitating sputum collection & transport.

He maintains a referrals register in line with the lab register and disseminates the patient charter, which is also prominently displayed in his clinic.

Mr. Maurya is also working as a DOT provider now, and regularly attends the quarterly meeting at the district level. This, he says, is an opportunity for him to share and discuss the issues he encounters as a service provider and have them sorted out with the relevant authorities.

Submitted by MAMTA
CASE STUDY

Bipin Nayak’s saga of struggle in conquering TB

The Gaon Kalyan Samitee (GKS), created under National Rural Health Mission, has been actively involved in village based health planning and monitoring the delivery of village health services across India. In the poor tribal village of Asanbani in Mayurbhanj district of Odisha, the GKS has been pro-active and caring towards poor TB patients. Their financial, social and health support to Bipin Nayak, a 40 year old physically challenged tribal, has been indispensable during his struggle against TB.

Bipin Nayak is a physically challenged man with has no source of income. Before TB, he survived on a paltry sum earned from herding cows for the villagers. His wife was too frail for labour, while his son was physically and mentally challenged as well. As per Laksmi Nayak, the village panchayat elected representative, who is also part of the GKS, “Bipin Nayak’s is the poorest and destitute family in our village. He was terribly sick and was bedridden in the middle of 2012. Being physically handicapped, mobility was a big problem for him to access to health services. Knowing of his family condition, the GKS unanimously decided to provide financial help from the untied fund of GKS to get over the financial difficulties.”

Bipin Nayak is one of the TB patients who was given cash support of Rs. 700 in two instalments - at the time he was diagnosed with TB and immediately after he was declared cured. This financial support enabled him to buy the daily necessities for subsistence and basic nutritional food, as he had persistent vomiting and nausea in the early stage of DOTS. In addition to this, the GKS also helped by taking Bipin Kanjasol Primary Health Centre (PHC), where his TB status was identified. He was then administered DOTS through the help of the village Accredited Social Health Activist (ASHA, who would go to his home knowing his disability to provide his treatment. GKS members particularly, Suganthi Behra and Sumitra Naik, who are also part of the Self Help Group (SHG) of the village regularly visited his home and provided social support to him and his wife. The local help rendered by GKS served as a cushion and relief for him to release from suffering wrought by TB.

Knowing the economic plight of Bipin and his family, Laksmi Nayak further helped get a physical disability certificate from the government (for him and his son), which opened the window for monthly disability pension and other entitlements. He is now availing Rs. 300 monthly pension payment, which is his lifeline now. The elected member also helped him to get the monthly ration quota of 35 kilos of rice from the Public Distribution System (PDS). The GKS has been backed by Alternative for India Development. The organisation has been supporting the GKS for the past three years in mainstreaming TB and to use the untied funds for helping the neediest patients through training, experience sharing, and sensitisation of the GKS members.

Bipin says, “I am alive and living with dignity because of the social and monetary support provided by the GKS, ASHA and the disability pension. This humanitarian gesture of GKS boosted my confidence and stamina to bear the pain of the disease. I have been able to conquer TB owing to the overwhelming support from GKS.”

Submitted by AID India

Sri Digdhan Gokhra

Mr Digdhan Gokhra, a 48 year old mason from Kolabira had been suffering from cough and mild fever for more than four months. He had no intentions, however, of going to the local CHC for a health check up.

Mr. Promod Porua, staff with SEWA organization, came to know of Mr Gokhra’s poor health and visited him at his home. Mr. Gokhra, who was reluctant about visiting any hospital, was told about the dangerous consequences the family and the neighbors will face in case he is suffering from TB. It was also stressed that TB is 100% curable, if treated properly. Nevertheless, Mr. Gokhra was adamant about not visiting the local CHC.

As an alternative, he was asked to suggest where he would prefer to go for a check-up. Fortunately, Mr Porua and Mr Gokhra discovered they had a common friend working in the TRL hospital in Belpahar. Mr. Gokhra then agreed to go a health check up at Belpahar, where he was advised by the doctor to take a sputum test. Subsequently, he was diagnosed as 3+ sputum positive TB patient in June 2012 and was prescribed for category 1 treatment.

The 6 month long DOTS treatment began along with counselling a week after he was diagnosed. He was declared cured in October on the basis of a sputum test.

From the above incident, it is clear that there was a lack of awareness in Mr. Gokhra, regarding the services available at the local health facility. Personal reasons notwithstanding, this is indicative of a deeper ignorance and distrust that many people still harbour towards government health services. While the government sector has been committed to improving the quality of health services available to the rural population, community mobilization through information and education campaign (IEC) and behaviour change communication (BCC) are equally the need of the hour.

Submitted by SEWA