Through our Health Programmes

- People newly diagnosed with and treated for leprosy: 5,337
- People treated for complications of leprosy: 13,807
- Number of reconstructive surgical procedures done for correction of deformities: 1,154
- Number of cataract surgeries done to restore vision: 2,918
- People with insensitive feet provided protective and specialised footwear: 12,335
- People from the community treated through our outpatient and inpatient services: 4,50,369

Through our Livelihood and Advocacy Programmes

- Teenagers from leprosy background (297 girls) trained in VTCs: 810
- VTC graduates placed in jobs with salaries ranging from Rs 3,500 to Rs 6,000 per month: 88%
- Students affected by leprosy able to continue education through financial support: 2,329
- NGO supported beneficiaries of our community programmes in accessing mainstream education and livelihood schemes: 19
- SHG members in 1,250 SHGs availed bank loans and started micro-enterprises: 10,012
- School children sensitised about inclusion of children affected by leprosy in mainstream activities: 73,058
- People with disabilities issued disability certificates and accessed their pension/eligible benefits: 119
- Community members demonstrated willingness to mainstream families affected due to leprosy: 6,916
- People affected by leprosy/general disabilities benefitted from train and bus concessionary passes: 1,537
- People with disabilities gained mobility with assistive devices: 524
Milestones of the Mission

1874: Wellesley Bailey, an Irish school teacher in Ambala, Punjab, saw the need of those affected by leprosy. “I felt that if there was ever a Christ-like work in the world it was to go amongst these poor sufferers and bring the consolation of the gospel.” The ‘Mission to Lepers’ was born in 1874 when friends of Wellesley and Alice Bailey promised to raise £30 a year to help people affected by leprosy in India; in the first year itself, £600 was raised. Many Leper Asylums or Homes started by European and American missionaries were handed over to ‘Mission to Lepers’.

These are the TLMTI hospitals that started out as Homes. Their early descriptions are home for leprosy beggars; home for leprosy destitutes; home for the outcast, etc. - 1879 Naini, 1888 Purulia, 1896 Miraj, 1897 Chandkhuri, 1898 Kotara, 1902 Bankura, 1902 Champa, 1904 Muzaffarpur, 1906 Salar, 1913 Dayapuram, 1925 Vadathorassulur and 1938 Faizabad.

1997-1937: For the first time treatment with Chaulmoogra oil brought widespread hope to people affected by leprosy. Injections are painful, and only a few are cured, but the aura of cure sees the outlawing of the word ‘asylum’, and the introduction of its replacement the ‘hospital’.

1950s: Dapsone began to be widely used and TLM Homes began their transition into Hospitals to meet the need for tertiary leprosy care – ulcer care, reconstructive surgery, treatment of reactions, neuritis and eye care.

1960s: TLM’s Leprosy Control work reached out to people in their own homes through the Survey, Education and Treatment (SET) programmes.

1965: Ninety one years after its beginning, the Mission changed its name to The Leprosy Mission to avoid the negative connotations of the word ‘leper’.

1980s: Multi Drug Therapy (MDT) replaced Dapsone monotherapy.

1980s: To meet the need of sustainable livelihoods for leprosy affected and disabled youth, TLM started its 1st Vocational Training Centre at Nashik. Six VTCs today ensure that these marginalised youth have better employment opportunities through improved access to Vocational Training and Skill Development.

1990s: Emphasis was given to Prevention of Impairment and Disability.

1990s: TLM India introduced Community Based Rehabilitation and various Community Based Projects have been implemented since then.

1994: TLM established the Stanley Browne Research Laboratory.

1999: The Diana Princess of Wales Health Education and Media Centre was established at Noida.


2005: Concept of Community hospitals began; today there are six community hospitals.

2011: A new Country Strategy is in place.

The Leprosy Mission Trust India is approaching 14 decades of work in India with relentless commitment as the largest International Non Governmental Organization, working for transformation and empowering the lives of people affected by leprosy. TLMTI has endeavoured to prevent disability, reduce stigma and discrimination, and restore dignity to people affected by leprosy.

TLMTI has its presence in 10 states in India through its 14 Hospitals; 14 Community Development projects; 6 Vocational Training Centres; 5 old age “mercy” homes (Snehalayas); a state-of-the-art Research Laboratory; a Media Centre for Advocacy, Communication and Education; and Public Health support to the National Leprosy Eradication Programme (NLEP) in 4 states of Maharashtra, Chhattisgarh, Delhi and Uttar Pradesh.
It is with immense pride that I present The Leprosy Mission Trust India’s (TLMTI) Annual Report 2011.

2011 has been another year of contributing towards ‘Transforming Lives and Transforming Communities’ at The Leprosy Mission Trust India.

Today as we stand at the threshold of a social transformation, we need to renew our commitment towards promoting social justice and a world without leprosy. This can only be achieved through prayers, passion and conviction.

Need of the hour is not to contemplate the global economic crises but to find solutions that can be transformative.

The focus of the Board in 2011 was on the new Country Strategy 2011-2015. The Country Strategy was reviewed in detail and focus was on sharpening our vision and repositioning ourselves to bring about transformation.

A challenge that we at TLMTI have embraced, to bring about a change in the way we work and find the fine balance between development and service. The challenges are enormous but our efforts in 2011 reflect that transformation and change internally and externally is possible.

It is with your prayers and the commitment and dedication of TLMTI’s employees and strong leadership, our programmes have touched millions of lives and made a lasting impact.

We are grateful to you for this support and for the opportunities to improve the lives of individuals, families and communities affected by leprosy.

With Prayers and Best Wishes,

Dr. D. P. N. Prasad
Chairman
TLM Trust India Board

“Today as we stand at the threshold of a social transformation, we need to renew our commitment towards promoting social justice and a world without leprosy. This can only be achieved through prayers, passion and conviction.”

It is with pleasure and a sense of achievement that I report what we, as an organization, did during the year 2011. The underlying theme for the year was ‘CHANGE’: this was driven by our new Country Strategy. This change was evident in our organizational re-structuring, our programme focus, our functioning and even in the culture of the organization - a desire to be more open to dialogue and discussions; to partnering with others; and most importantly, to learn.

The greatest achievements were the development of the Country Strategy in a very participatory manner and the sensitization of key leadership in the field to the strategic priorities and the need to change the way we function. I believe there has been a general buy-in to implementing this Strategy.

Linked to the Strategy was the re-structuring of the organization which was accomplished smoothly. Almost a year after the re-structuring, I feel that the new structure is delivering and driving the change we envisaged.

Another significant achievement was the salary revision that was done this year despite the financial constraints. Though the significant salary revision had meant that there would be added financial pressure, it was long overdue and necessary.

Challenges during the year have been plenty, the most significant of them being finances. The reduction of grant from TLM International due to global recession and our inability to raise local resources to match that reduction meant that we were constantly under pressure to find resources to fund our operations. The challenge to recruit key professionals, (especially doctors) for our hospitals, VTCs and projects in backward and rural areas is never ending. But through it all I have had the assurance of God’s presence and direction.

The achievements of the past year and the way we faced challenges are a result of the commitment and hard work of all my colleagues in the Mission and the support and encouragement given by the Chairman and Members of TLMTI, our Donors, our various Partners and Members of TLM Global Fellowship whose support, prayers and encouragement we value.

I thank God for His faithfulness because of which we not only look back in gratitude at the past year but also look ahead with faith and hope at the challenges we face in the coming year.

Dr. Sunil Arunad
Director
**The Context**

TLMTI, over the last 138 years, has continued to respond to the needs of people affected by leprosy. Much has changed in the recent past in terms of needs and expectations of people affected by leprosy: integration of leprosy services with general health services (and its resultant decreased focus on leprosy); TLM Global Fellowship; civil society movements on issues of social exclusion, dignity and justice, to name a few. The need of the hour is to reposition our traditional methods and approaches to ensure sustained impact on the lives of people affected by leprosy.

**TLMTI’s Country Strategy 2011-2015**

envisages changes in our programmatic approach from ‘service delivery’ to ‘holistic development’ with a balance between ‘implementing’ and ‘influencing’. It calls for greater accountability, ownership, resource mobilisation and reflective learning to grow as an effective organisation.

**Realigning TLMTI’s Country Programme to its Strategic Priorities Processes, Highlights and Challenges 2011**

**Organisation Structure and Staffing**

The well researched and revised organogram was shared with the country programme leadership during the Annual Consultation of TLM India Leaders in January 2011. Subsequently, positions of Deputy Directors and Domain Heads were filled with suitable candidates from within and outside the organisation. Programmatic and support functions were brought under different domains such as: Health, Sustainable Livelihoods, Community Development, Media & Advocacy, Research, Monitoring & Evaluation, Knowledge Management & Development, Finance, Audit & Risk Management and Human Resources. Towards developing personal competencies of the Operations Team members, a four-day workshop exploring individual and organisation realities was conducted through external facilitation.

**Country Strategy Implementation and Sensitisation Process**

The Country Strategy 2011-15 was approved by TLM Trust India Board and a broad plan of implementation was developed. A 3 day ‘Training of Trainers’ workshop was conducted in May 2011 in Delhi for the Operations Team and a group of senior staff members. What ensued were five regional sensitisation workshops in different parts of the country involving TLM local leadership and key influencers from each of the programmes. The State is taken as a Unit for maximising our impact. Units/projects within each State met and discussed ways of interacting and coordinating among themselves to maximise resources and impact at district and state levels.

**Mid-year Programme and Budget Review**

The strategic shift of our work demanded re-working the 2012 budgets and the multi-year plans. The exercise was tuned to aligning the programme shift and the budget requirements in the light of reduced financing from TLM International. The reduction in available grant from TLM International (TLMI) called for a sudden urgency to manage cash flows with greater care. At the same time, the additional cost of revised salaries added to the strain on finances. Regular flow of information and dialogue between TLMTI Country Office, Units, Senior Management Team and TLMI enabled us to manage the financial challenge.

It was a tough challenge for all. The sensitivity to change was evident in the presentations shared by the Units/Projects with the senior team. This facilitated mutual support, learning and ownership.

Major issues discussed were state level implementation plans, strategic partnerships for widening our influence (with special emphasis on Government schemes) refocussing our work and consequently staffing, budgetary controls and financial accountability of local managements, need for funding capital expenditure and local fundraising. Majority of the units successfully sailed through well, with the challenge being not to exceed their projected expenditure budgets. Exceptions were analysed at the end of the year and corrective actions resorted to.

**Revised Salary Structure**

The revised salary structure arrived at through a benchmarking exercise and rationalisation of pay scales, designations and benefits and allowances was implemented with effect from January 2011.

**Partnerships**

2011 has been of great significance for partner institutions since developing Strategic Partnerships is one of the key strategic priorities for TLMTI as stated in its Country Strategy 2011-2015. This will open a whole new dimension in the area of strategic partnerships and will bring in an entire paradigm shift in the existing partnership concept.

TLMTI’s 31 partners are spread across 12 States in the country. Through them TLMTI has greater outreach to people affected by leprosy in other areas. The partners include 12 hospitals, 15 community based organisations (NGOs) and an organisation which is solely involved in publishing leprosy related journals.

The year 2011 has been one of change, and we are proud of our accomplishments and journey so far that has impacted more than a million lives. As we move ahead we are committed to re-positioning ourselves to deepen our impact and pursue a more effective holistic approach to transforming the lives of people affected by leprosy and their communities.
As part of organisational restructuring, TLMTI has instituted organisational effectiveness in 2011. All the support services to the Programme have been brought under one umbrella so that the synergies across the support functions are enhanced and programme delivery in the field is made effective. The domains under Organisational Effectiveness include HR, Finance, Audit & Risk, Knowledge Management & Development, IT, Spiritual Nurture, Terminal Benefits, Monitoring & Evaluation, Properties and General Administration.

Finance
The changes brought about by the Government through the Foreign Contribution Regulation Act 2010/Rules 2011 and the implication of the same for TLMTI and Supporting Countries. Necessary affidavits to secure our risks in grant transfer to our local partners were also taken.

Human Resources
The need to equip our staff to take forward the Country Strategy was recognised. A Staff Capacity Development proposal to the Swedish Mission Council was made. The objective was to bring out learning from the field to strengthen organisational systems and methods.

Audit & Risk Management
The Country Strategy also has implicit risks for its successful implementation and impact. With many areas of work envisaged in the Country Strategy moving on to newer avenues and directions, the need to re-look at the country risk matrix was felt. The Country Risk Register was prepared highlighting emerging risks and possible mitigation plans. The audits as planned were completed and the function also undertook special audits whenever there was a request. The idea is to facilitate each process owner in the system to audit his or her own work through a self-assessment audit and thus build up self-assuring controls.

Monitoring & Evaluation
M&E in TLMTI is viewed in terms of creating learning for the organisation as a whole as well as giving strategic feedback for individual units and the organisation. In 2011, four Hospitals, a Media Centre and seven Community projects of TLMTI were evaluated. In addition, the function had taken up the design of a country programme monitoring framework in line with the new Country Strategy.

Communications
TLMTI communication strategy was strengthened through various events, activities and greater visibility in the media. TLMTI’s state-of-the-art Media Centre produced posters, booklets, a monthly magazine, films and radio programmes to raise awareness and educate the masses on the issue of leprosy. It also organised press conferences and events to create awareness. To reach out to the youth, TLMTI enhanced its social media presence through Facebook and Twitter and the online outreach witnessed tremendous response.

Fundraising
Our primary focus this year was to build a winning Fundraising Model and to build the capacity of our team through various workshops on strengthening staff skills and planning out fund raising strategies.

Leprosy is curable, and if treated early, the consequences of leprosy are preventable. However, many people affected by leprosy are unable to access quality health care.

TLMTI Hospitals
Our 14 hospitals provide high quality, specialised care in urban and rural areas across India. The wide range of services include provision of Multi Drug Therapy, management of reactions and neuritis, care of insensitive extremities, eye care, specialised foot wear, orthopaedic appliances (e.g. crutches) and artificial limbs, correction of deformities through surgery, physiotherapy, occupational therapy, counselling, training in prevention of further disability and general health education.

Four of our hospitals serve the community through providing obstetrics services, and all our hospitals work with people with disabilities, due to leprosy or other causes.

Five of our hospitals provide eye care to general community is provided by, through ophthalmology units.

Many of our hospitals are in remote, rural areas within reach of the most marginalised communities. In addition to providing services to people affected by leprosy, they also provide health care to other disadvantaged groups in the local community.

The year 2011 saw increased coherence and co-operation between hospitals and other TLMTI units of each state. This was further strengthened by developing the state implementation plans with the units in the light of the leprosy situation in each state.

We also focused on moving outwards from a leprosy centred perspective to using our skills in other aspects of health care, specifically into dermatology, general medicine, management of disabilities and ophthalmology.

The new Country Strategy helped us realign our strategic core focus towards a more holistic approach with hospitals viewing each individual affected by leprosy as a person with many needs and not just as a patient in need of health care.

Programme Highlights
In 2011, our hospitals saw a total of 13,807 people affected by leprosy. The total number of new cases for MDT in our hospitals was 5,337. Hospitals in Shahdara, Purulia and Champua have shown significant increases in numbers, but the others have shown a decreasing trend.
Disability rate among new cases was 37%. The rate of child patients among those registered for MDT was 12% and the female patient rate was 28%.

Admissions for management of complications showed a static trend with ulcers continuing to be the main reason for hospitalisation. There were a total of 7,532 admissions. The admissions due to ulcers were 3,037; reconstructive surgeries accounted for the next most common cause for admissions accounting for 1,695 admissions. Reactions and neuritis accounted for 890 admissions.

A total of 2,794 complicated ulcer debridement procedures were done. The ulcer recurrence has been about 10%. Supply of MCR footwear was 9,513 pairs.

Thousand twenty eight reconstructive surgical procedures were done. More than 96% of patients operated had shown improvement in function and appearance.

Non-leprosy outpatient visits were 464,564 and 10,091 non-leprosy patients were hospitalised. The average number of non-leprosy inpatients per day in our hospitals was around 132.

Number of cataract surgeries performed were 2,918. Assessments of the surgeries show that 99% of patients operated had their vision restored.

Raising awareness and empowering the rural community through village clinics
We continued to conduct village-level clinics to raise awareness about leprosy and other health issues, including malaria, tuberculosis, HIV/AIDS. We teach communities good health practices (e.g. hand washing), particularly for mothers and children (e.g. breast feeding).

Prevention of Impairment and Disability comes high on the priority list of TLMTI, given the fact that the timely preventive care by way of health education significantly reduces the chances of Impairments and disabilities in leprosy.

Snehalayas
Five Snehalayas (Mercy Homes) provide full-time care for elderly people affected by leprosy, who have been disowned by their families and excluded from their communities. A holistic mix of physical, psychological and spiritual care is provided to enable them to live their lives with dignity and love.

Public Health
Strengthened engagement and collaboration with national and State governments to enhance the quality of health systems and the knowledge and skills of health staff to ensure quality care for people affected by leprosy is a strategy adopted by us in four States (Maharashtra, Chhattisgarh, Uttar Pradesh and Delhi) under the National Leprosy Eradication Programme (NLEP). We continued working with Health Department staff to improve referral systems with tertiary leprosy hospitals and also work with the government to monitor and evaluate the impact of programmes in these four States. The specific areas of thematic support to NLEP include:

1) Capacity Building
2) Disability Prevention and Medical Rehabilitation (DPMR) and referrals
3) Monitoring and Supervision
4) Socio-Economic Rehabilitation (SER) and Community participation
5) Operational Research

Capacity of grassroots health workers in Chhattisgarh state was built through training programmes under the World Health Organisation (WHO) supported project. A manual in the local language to aid diagnosis, treatment and management of complications of leprosy was also brought out.

Integrated Health and Development (IHD) projects in Kothara and Sakat (through partnership with CBM) and Vazhunthukavom project in Vadathorasulur (through partnership with the state government) addressed health and development issues of target communities. Activities under these projects included:

1) Training community volunteers and AWWs (Accredited Social Health Activists) and ANMs (Auxiliary Nurse Midwives) in aspects of health care such as diagnosis and management of leprosy, malaria, diarrohoea, maternal and child health and eye care.
2) Identifying and referring children with disabilities for care, counselling and education.
3) Setting up of village health committees to oversee health programmes.
4) Formation of new self help groups and strengthening of existing ones.
5) Creating awareness among the tribal population and rural communities about available government schemes for individual and family development and helping people access these benefits.

The programmes were started as pilot projects in Kothara and Salur in 2011, for about six villages in each area, and are expected to include 24 more villages depending on our experience from this approach. In Vadathorasulur, the project was completed (but renewed for 2012 with expansion into other districts).

Prevention of Impairment and Disabilities
TLMTI’s focus and emphasis on home based self care teaching for patients affected by leprosy have been fruitful in reducing and preventing the occurrence of new impairments and secondary deformities. The multi-skilled team approach of the POID staff in the hospitals help the patients with secondary deformities to confront the constant challenges faced in their normal activities of daily living. Efforts have been taken to work along with few National Institutes in designing, developing and procuring aids and appliances for differently abled patients coming to TLMTI. Disability assessment and the individual tailor made rehabilitation plan developed by the Occupational therapists for the differently abled students of the TLMTI’s Vocational training centres have motivated and encouraged the students to opt for careers which were only unfulfilled dreams earlier.

The inputs from the experienced staff and the induction of new staff together have helped bring in unmarked changes in the way of implementing POID in TLMTI.

Making sure that everyone is treated
(Stories from TLMTI’s Public Health support to NLEP in Chhattisgarh)

The Technical Resource Unit of Chhattisgarh visited the Primary Health Centre of a block in Raipur district. While going through treatment cards of the patients, they came across a patient who was taking treatment regularly every month beginning from December 2010 and had been cured. There were two more cases from the same village that needed validation. When the team consulted General Health Care staff and our staff found a patient, they discovered that he had taken only two doses of MDT & stopped treatment. Now he was in reaction. The Physiotherapist counselled him and convinced him to restart MDT. The patient is continuing treatment from the PHC.

While visiting a patient in a village in another block, the Anganwadi Worker (AWW) of the village requested the team to see a lady who was put on MDT and stopped it after 2 months of taking it. The team found out that the lady had stopped treatment after getting fever, linking it to be a reaction due to the drugs. She was counselled by the team and was put on MDT again. She is taking the MDT regularly since then.

AWWs are being encouraged to follow up defaulters in their respective areas and are a great help to the programme.

"Now, I can pursue my studies and become a teacher.”
Nisha, after reconstructive surgery on her hand

Nisha, 22 years old, is from Pratapgarh, Uttar Pradesh. When she was in the 12th class she developed anesthetic patches on her legs. Her parents took her to quacks and doctors and spent a lot of money, but to no avail. Her hands slowly developed clawing of the fingers and she had to quit studies.

"In March 2011, I was diagnosed with leprosy at TLMT Nainital hospital. Now I am cured and my claw hand also got operated and corrected. Now, I can pursue my studies and become a teacher," she said.

With support from TLMTI, she is planning to join college and also spread awareness on leprosy in the community.

Ensuring quality care & early detection through PHCs

Wind Beneath Her Wings

"Nisha, after reconstructive surgery on her hand"
TLMTI believes that meaningful progress towards sustainable human development, inclusion and stability can be achieved through measures that promote and protect human rights and ensure effective participation of the marginalised in society.

Our Sustainable Livelihood programmes work for/with people adversely affected with leprosy, individuals with general disabilities and others marginalised due to gender, caste, backwardness and those who do not have a regular and assured income.

The key strategies of our Sustainable Livelihood Programme focuses on building vocational and work-related skills because TLMTI believes that sustainable livelihood activities are the only long-term solutions to enable the marginalised to work their way out of poverty and ensure a secure future.

**Education:** Our education for sustainable livelihoods encompasses broad-based capacity development, including both formal and non-formal education systems at all levels.

**Vocational Training Centres:** Our six Vocational Training Centres (VTCs) train the most deprived and vulnerable young people and adults affected by leprosy and general disabilities, in trades and skills which meet both the market demand and the specific physical needs of people affected by leprosy (e.g., disability, limited mobility, etc.). These VTCs also support the students in being gainfully employed (both self and waged) by providing placement assistance.

- Of the 810 that graduated from our six VTCs in 2011, 713 (88%) are gainfully employed.
- In the academic year 2011-2012, 805 students were admitted to various trades. Of these 188 (23%) are affected with leprosy while 532 (66%) are children whose parents are affected with leprosy. The number of students with leprosy related disabilities across the six VTCs is 91 (11%).

Introducing ‘Community Based Vocational Training’ (CBVT) was another major achievement in 2011, which saw the VTCs repositioning themselves to reach out to more people. Two hundred and thirty five individuals (youth and married women) have received/are receiving training and employment support in mushroom cultivation, silk thread weaving, computers, mobile repairing and tailoring. CBVT is unique as it promotes community-based solutions in linking skills, training and sustainable livelihood (both self and wage employment) for the most vulnerable communities, especially those who cannot access TLMTI’s VTCs. Importantly, community groups formed by the programme played a key decision-making role in the planning and implementation of the programme.

**TLMTI’s VTCs raised awareness and advocated to promote fair labour conditions, and safe and appropriate working surroundings and facilities.**

**Economic Independence and Empowerment**

A vast majority of people affected with leprosy and general disabilities with whom we work are in the informal sector of the economy, having no steady income or any kind of security and are living in extreme poverty.

Through our projects we enhanced their capabilities and provided secure livelihoods. We focus on creation of Self Help Groups (SHGs) to ensure equality, economic benefits through income generation and create solidarity. The aim was to federate the SHGs for their long-term sustainability.

The 1,250 SHGs formed through various TLM Livelihood projects continue to be given requisite skills training in entrepreneurship, life skills and technical skills pertaining to their enterprise and functional literacy where needed.

New livelihood opportunities were created by promoting enterprises such as poultry farms, dairy farms and weaving cooperatives. TLMTI provided appropriate handholding support to SHGs to develop their business plans and link with banks for credit support. This empowered members of the SHGs to become more effective providers for their families.

The SHG members have also been capacitated to take up issues that affect the lives of the people in the community. These groups along with community volunteers and TLMTI were actively involved in intensifying community action by mobilising other community-based organisations along with them.

One of our projects specifically works with artisans with disabilities to enhance their skills, increase competitiveness and meet the demands of the local market, access government services and form advocacy networks.

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**Sixty-year-old Ram Kailash from Ramgarh in Digha, Allahabad, lost his left foot due to leprosy ulcers a few years ago. His family spent most of their money on his treatment in various private hospitals, over the years. Ram Kailash and his entire family was left struggling financially with no help from anywhere.**

The Socio Economic Rehabilitation Programmes of The Leprosy Mission took on to help Ram Kailash and his family. Along with being fitted with an artificial limb, he was given a buffalo and financial aid to sustain his family. With this help, Ram Kailash and his family live a better life.

"The socio-economic rehabilitation programme provided us with a new lease of life."

Ram Kailash
Community Based Rehabilitation and Self-Care

With traditional prejudices continuing to have a strong hold on the perceptions of the general community, rehabilitation of the leprosy affected poses a challenge even as we put in consistent efforts to improve the quality of life and help people affected by leprosy to live a life of dignity. We worked with communities to build their understanding of leprosy and disabilities and their capacity to support people affected by leprosy or with disabilities during their rehabilitation. Our Self-Care Groups (SCGs) brought together people with leprosy-related disabilities to prevent further injury at work place or home. SCGs spread awareness about disability rights, and offered a forum for people affected by leprosy to meet, share experiences, discuss issues and support each other.

Low Cost Housing

Many individuals affected by leprosy are unable to afford adequate shelter or gain a loan from the bank to build a shelter. TLMTI supported such individuals to build secure houses in their communities.

“... provided us with Low Cost Housing after I lost my foot due to amputation.”

Bheem

Bheem, lives in Kalampur Village of Gonda District with his wife and two sons. Bheem’s treatment for leprosy was started in Faizabad and later moved to Naini. Unfortunately, the ulcer was still not cured and his left foot had to be amputated, leaving him physically handicapped. Hailing from a poor background, the family’s living conditions are not very good. The only income of the family came from his wife who did manual labour to sustain them. It even became difficult to keep his sons in school.

TLMT Hospital Faizabad referred Bheem to the CRP Project and his family was provided with a Low Cost House as support.

Leprosy is a more visible disease compared to other stigmatising diseases like HIV/AIDS and TB. The visible disabilities, unpleasant ulcers and superstitions related to social, cultural and religious practices, make people affected by leprosy more vulnerable to being stigmatised in society.

The policies of exclusion such as separate leprosy colonies and hospitals for treatment have done great damage and disservice to people affected with leprosy and reinforced the wrong belief that isolation is the best way to control leprosy. Anti-leprosy legislations further aggravate discrimination of such people.

We specifically work on:

- Reduction of Stigma, ending discrimination and violation of Human Rights.
- Increasing and facilitating access by all persons affected by leprosy and other disabilities to government benefits, services and health care.
- Ensuring rights of people affected by leprosy and other disabilities to have work opportunities consistent with their interests, abilities and needs.
- Promoting the rights of people affected by leprosy to lead a better life and ensure equal provision in all services.

TLMTI’s strategy aims at creating an enabling environment for people affected by leprosy to take collective action to challenge legislation which discriminates against them. Changing the attitudes of people in their communities is the only sustainable way to reduce stigma and protect their rights in the long term.

Policy Advocacy for repealing anti-leprosy legislations

TLMTI moved from being the “voice of the voiceless” to support the “voice of the marginalised and the vulnerable to be heard by the decision makers” through its DFID-supported project, Challenging Anti Leprosy Legislations and Discriminatory Practices (CALL). The project strives to empower people affected by leprosy to advocate at the national and state level for the repeal of discriminatory laws. This was done by forming networks and mobilising them, at both state and national levels.

Advocacy through networks at state and national level

In 2011, we recognised the need to bring about wide-ranging social change and opportunity to enable people affected by leprosy to advocate at the national and state level for the repeal of discriminatory laws.

Highlights

1. Ram Singh, helped by TLM Socio Economic Rehabilitation Project to set up his own grocery shop.
2. Ajjan Begum, was able to open a bank account and get a job card with the help of CALL project.
3. Helping people affected by leprosy like Dhondi, to fulfil their dreams through TLMTI’s Income Generation Project.

TLMTI’s strategy aims at creating an enabling environment for people affected by leprosy to take collective action to challenge legislation which discriminates against them. Changing the attitudes of people in their communities is the only sustainable way to reduce stigma and protect their rights in the long term.

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by leprosy and their family members to end social and legal discrimination faced by them - an established constituency of 10,172 leprosy affected persons and their families in two states of UP and Chhattisgarh. Thus a network is being established with the leaders of leprosy colonies in UP (63) and the first draft of the Charter of Demands is under circulation.

**Strengthening coordination for effective advocacy**

About 45 key staff members from all our projects, programmes and field areas participated in two national advocacy workshops. The workshops sensitised them to the concept of advocacy for the differently abled, including the leprosy affected, to access basic facilities as the primary rights of the stakeholder. School children were empowered to take up the challenge of raising awareness.

Interventions through projects like ‘Schools Targeting Stigmas’, UP increased awareness on diseases like Leprosy, TB & HIV/AIDS among school children. They, in turn, through their Peer Educators, spread their knowledge about these diseases to other students and to the neighbouring communities. The project further networked with CBOs and NGOs to ensure sustainability and continuity of the project impact.

Increased public awareness and opinion that leprosy is curable and early detection can prevent disability was delivered through street plays, health camps and various IEC materials produced at the Media Centre. Materials like posters, booklets, films and documentaries, radio programmes, jingles and folk songs were produced, broadcast and distributed to raise awareness about the symptoms and treatment of leprosy and other diseases such as malaria, tuberculosis, cancer and HIV/AIDS.

**Media and Press**

The Media Centre has organized three regional press conferences at Bareilly, Moradabad and Patna on Human Rights and Dignity for Leprosy Affected People highlighting discriminating lines on leprosy. The pathetic situation of the leprosy affected people living in 63 colonies of Bihar was brought to the notice of the government through the media. A strong demand was made to the government for the Pension and livelihood projects for the leprosy affected people in Bihar.

**ASTORY OF MILLS AND LOOMS**

This is a true account of the weavers from Korguda, Durg, in Chhattisgarh.

Fed up with the bad working conditions and insufficient work opportunities of being a labourer, Lubhan and 58 other men joined the Jai Budha Dev Adivasi Weaving Co-operation. With 25 looms set up in the village by the Handloom Cooperative Society, Lubhan who used to struggle with a spade has learned to work skillfully with threads and looms.

Lubhan and his clansmen are descendants of the Gond and Halva tribes – some of whom were traditional weavers. In 2007, they formed a handloom society with 21 members that became defunct due to lack of co-operation and unity. TLMTI’s strengthening of the Self Help Group (SHG) Project helped them form Self Help Groups and revive the society with even more members – five of whom have a background of leprosy and other physical challenges.

With a preliminary loan of one lakh Rupees, the society set up handlooms and shifted to making plain white cloth from the traditional sari-making as it has a bigger market and demand. Raw materials are provided by the state level apex society that also buys back the finished product. Volunteers look after the training and progress of 14 SHGs in the area. The society is even looking to expand their work space.

**THE WEAVERS OF KURINCHIPADI**

Handloom weaving is still a household industry as well as a predominant source of income in Meenachippati village of Kurinchipadi since 1953. Unfortunately, the weaver work force has dropped from 30,000 to merely 2,000 today.

Income earned depends on the number of looms and workers in each family. However, the families that rely solely on weaving earn less because the cost of raw materials is high. They are unable to bear the cost of running power looms. The low market price they got for their product continues to keep them in poverty.

TLMTI’s CRAFT project countered the problems with skill enhancement and diversification but was able to motivate the weavers to partner with TLMTI. Fortunately, the project gained the interest of a family of 12 with three differently abled artisans.

The family resides in three independent huts and has four pit looms. The family has been taught to understand and apply a handloom designer’s specifications. The use of different yarn counts has reduced production time and increased quantity. One of the four pit looms is even used for experimentation. Products like cushion covers, aprons, curtains and apparel are being developed and a tie-up with Fashion Export resulted in the successfully meeting their first big production order.

**“We all have our own life to pursue, our own kind of dream to be weaving, and we all have the power to make wishes come true, as long as we keep believing.”**

Louisa May Alcott

**“Man does not weave this web of life. He is merely a strand of it. Whatever he does to the web, he does to himself.”**

Chief Seattle

The development strategies include weaving assessments, product development, packaging, tailoring and even working with the marketing staff of TLMTI’s CRAFT project to develop marketing and promotional material.

All in all, the project has developed a good rapport with local societies and has helped them in improved productivity and establish a unit that would make and convert fabric to finished product.
At the community level we raised awareness about the rights and entitlements of people affected by leprosy, the differently-abled and the marginalised women.

We inspire, inform and mobilise

Training programmes were organised to strengthen organisations of the differently-abled and the marginalised, to create suitable criteria for the leprosy affected persons to access disability ID cards. This would help them gain access to a number of welfare schemes. Leprosy affected persons with deformity lose their livelihood options even before they are 30-35 years.

Special drive to ensure entitlements

Special (Aadhart) camps for the persons with leprosy and disability were organised to help them procure their identity cards. This ensured their identity and helped them access facilities from financial institutions and other Government schemes.

The CBM supported Integrated Health Development Programme at Salur (Andhra Pradesh) and Kothara (Maharashtra) aimed at improving access to healthcare and facilitated health-related services in remote tribal areas.

We enable and encourage empowerment of the primary stakeholders through projects like:

Women’s Empowerment Programme in Uttar Pradesh (WEP-UP), Integrated Community Development Programme (ICDP) in Delhi, Transforming Communities and the Sundarban Community Development Programme (SCDP) in West Bengal.

Key Highlights:

Through formation of CBOs in slum communities, ICDP supported people affected by leprosy and other disabilities to link up with government departments for disability ID cards, referring suspected cases of leprosy to government hospitals, organizing slum and general health camps.

Mobilising Youth groups:

As part of awareness programmes on leprosy, HIV/AIDS and drug addiction, ICDP formed a group of young people to be trained as artists for street plays. This became a source of income for the youth members. STS-UP hired this group for other shows in Moradabad.

Demand for pre-schools in Delhi Slums:

Demand for pre-schools increased as the children were encouraged to go to school at the age of six. Pre-school teachers were regularly trained on innovative techniques to impart education through “joyful learning” which further motivated the children to attend the pre-school everyday.

Ensuring municipal support through a network of NGOs. Twelve NGOs rallied around the distribution of safe drinking water which gained the support of the entire community. The Jal Board of Delhi was pressurised to lay a new pipeline for drinking water supply to the communities.

Toilets for differently-abled women:

Construction of toilets for the differently-abled women and teenagers brought about a feeling dignity, security and privacy. This increased the demand for toilets for the women in the villages of Ramnagar and Fathepur (WEP-UP).

Literacy Classes:

Women and men in all programmes benefited from literacy classes. Neoliterate women initiated the task of wall writings to spread messages on health.

Environment:

Focusing on environment, women were empowered to keep their villages and slum surroundings clean. Vermicompost project was undertaken by ‘Women’s Empowerment Project’ (WEP) of UP, which brought about a considerable improvement in their living conditions. Introduction of kitchen gardens have supported families in increasing nutrition level among children.

Shivpyari, a 35-year-old member of the Mahila Mandal in the Gaurampura village located at the Farehpur Block of the Barabanki District. As part of the Empowerment of Village Women Project, started by The Leprosy Mission Trust India in 2009, a Leprosy Awareness Camp was held in her village.

It is at the Awareness Camp that Shivpyari suspected she had leprosy. She went to a TLM Volunteer to show her the patches on her body. The local Primary Health Centre near the village diagnosed her with leprosy and she is now undergoing treatment. The awareness programme not only helped her understand the disease but has also helped eradicate the stigma attached to leprosy in her village.

“I got cured of leprosy because of early diagnosis. I am grateful to TLMTI for giving me back my life.”

Shivpyari, Mahila Mandal member

Harkumari, proud owner of her own tailoring unit after studying in TLMTI VTC

Usha, disowned by her husband was treated at TLMTI hospital for leprosy, TLMTI VTC for life skills and later provided with a tailoring machine to become financially independent.

Reshma, a differently abled person and a member of SHG feeling empowered, after receiving an assistive device through a TLMTI project.

TLMTI
Research is one of the main priorities in the new Country Strategy 2011-15. Research in TLM involves laboratory research in molecular biology and immunology, clinical research at the hospitals as well as social science research in the field.

2011 has proved to be an eventful year for research in TLM, both at the Research Resource Centre and at the Stanley Browne Research Laboratory.

Stanley Browne Laboratory
Our state-of-the-art molecular biology laboratory conducts research on various aspects of leprosy, such as environmental Mycobacterium leprae and transmission link in leprosy; identification of bio-markers for leprosy; seasonal effects on transmission, study on cellular mechanisms in reactions to help identify predictors for nerve damage and surveillance of drug resistance using molecular techniques. These studies are progressing well.

Research Resource Centre
Research Resource Centre (RRC) continued its efforts to orient and encourage staff to make research a part of their daily work, by holding mini-workshops at different TLMTI centres (Shahdara, Naini & Kotshara) during the year. RRC also supported staff in submitting proposals to Indian Council of Medical Research for several multi-centre studies into clinical, operational and rehabilitative aspects. RRC focused on research areas which were designated as a priority by the Government of India National Leprosy Eradication Programme (NLEP) and ILEP. RRC continued to support TLMTI centres involved in research with technical expertise and research paper writing.

Highlights
An RRC workshop was held at New Delhi in May giving senior staff members of TLMTI an opportunity to interact with International experts and learn about the leprosy research scenario and get orientation regarding ongoing projects and activities. Another workshop was held in collaboration with ICMR to facilitate implementation of research findings from all organisations involved in leprosy work in the National Leprosy Eradication Programme (NLEP). Some important multi-centre projects were completed during the year and reports published. These were:

- The CARRELS Study on Community Action to Reduce Stigma which showed that Community action to reduce stigma at the village level was effective.
- The PELSI Project was completed. It had three parts - A population based rural registry, Household Sample surveys and effect of disability on a patient's life, in quantitative terms (DALY).
- A number of single centre studies - on disability, reactions and ulcer care.
- Study of environmental mycobacterium leprae and transmission link (ICMR Funded)
- A longitudinal cohort study to identify immunological biomarker for leprosy (ICMR Funded)
- Study of anti-inflammatory mechanisms that could help to identify predictors for nerve function impairment during leprosy reactions (ICMR Funded)
- Drug resistance in leprosy (will be approved for fund from Govt. of India)
- Molecular epidemiology of leprosy (submitted to ICMR for funding)
- Study of seasonal effects on nasal carriage and mucosal immunity in leprosy (TLM Funded)

Papers Published
- Papers on CARRELS, PELSI.

Nerve Function Impairment
- A new Multi-centre study on Urban Leprosy, supported by ICMR was initiated.
- RRC continued the Publication of a quarterly newsletter with latest research activities at TLMTI and news from the leprosy world.

TLMTI staff had submitted 10 concept papers to ICMR in response to a call for proposals from the Task Force on Leprosy, and of these 5 have been provisionally accepted.

Ongoing Research Projects
- A Research workshop was held at New Delhi in May giving senior staff members of TLMTI an opportunity to interact with International experts and learn about the leprosy research scenario and get orientation regarding ongoing projects and activities. Another workshop was held in collaboration with ICMR to facilitate implementation of research findings from all organisations involved in leprosy work in the National Leprosy Eradication Programme (NLEP). Some important multi-centre projects were completed during the year and reports published. These were:

- TASK Study on Leprosy expertise in TLMTI was carried out. A new Multi-centre study on Urban Leprosy, supported by ICMR was initiated.
- RRC continued the Publication of a quarterly newsletter with latest research activities at TLMTI and news from the leprosy world.

TLMTI staff had submitted 10 concept papers to ICMR in response to a call for proposals from the Task Force on Leprosy, and of these 5 have been provisionally accepted.

Papers Published
- Papers on CARRELS, PELSI.

Papers Published
- Reports on CARRELS, PELSI.

Ongoing Research Projects
- A number of single centre studies - on disability, reactions and ulcer care.

Stanley Browne Laboratory:
- Study of environmental mycobacterium leprae and transmission link (ICMR Funded)
- A longitudinal cohort study to identify immunological biomarker for leprosy (ICMR Funded)
- Study of anti-inflammatory mechanisms that could help to identify predictors for nerve function impairment during leprosy reactions (ICMR Funded)
- Drug resistance in leprosy (will be approved for fund from Govt. of India)
- Molecular epidemiology of leprosy (submitted to ICMR for funding)
- Study of seasonal effects on nasal carriage and mucosal immunity in leprosy (TLM Funded)

Awards
Mr Sundeep Chaitanya V. and Mr Samuel Raj K. from Stanley Browne Laboratory attended a conference on ‘Advances in Molecular Techniques & their Application in Health and Diseases’ and were awarded 1st prizes in different categories.
TLMTI Board of Directors
Dr. D P N Prasad - Chairman
Mr. G L Warne - Ex-officio Member
Mr. Jim Oehrig - Ex-officio Member
Dr. Sunil Anand - Director for India - Ex-officio Member
Dr. V P Macaden - Medical Consultant - Ex-officio Member
Dr. Nalini Abraham - Member
Dr. Vijay Aruldas - Member
Mr. George Koshi - Member
Mr. B S Chakranarayan - Member

Senior Management Team
Dr. Sunil Anand - Director for India
Dr. Mary Verghese - Deputy Director - Programmes
Dr. PLN Raju - Deputy Director - Organisational Effectiveness
Dr. Rajan Babu - Medical Advisor

Operations Team
The Operations Team of TLMTI looks after various domain areas of our work.
Dr. Jerry Joshua - Health Programmes
Mr. Samuel Thomas - Finance
Dr. Shyamala Anand - Monitoring & Evaluation
Ms. Rebecca Katticaren - Community Development
Ms. Tina Mendis - Sustainable Livelihoods
Mr. Joshy Jose - Knowledge Management & Development
Mr. Benison Solomon - Audit & Risk Management
Ms. Nikita Sarah - Media & Advocacy

Advisors
Mr. B Patnaik - Human Resources
Mr. Balhan Sagar - Fund Raising

Most of you are already familiar with our Board, Senior Management Team and Operations Team. Our team at TLMTI comprises of 1100, committed and diverse professionals from across all sectors with core specialities like doctors, nurses, scientists, educators, trainers, social workers, advocacy officers, drivers, cooks, etc working across 10 States to help us achieve our vision, “people affected by leprosy living with dignity in transformed communities that have overcome leprosy”.
Financial Highlights

BALANCE SHEET AS AT 31ST DECEMBER 2011

<table>
<thead>
<tr>
<th>Rupees</th>
<th>Rupees</th>
</tr>
</thead>
<tbody>
<tr>
<td>As at 31.12.2011</td>
<td>As at 31.12.2010</td>
</tr>
<tr>
<td><strong>SOURCES OF FUNDS:</strong></td>
<td></td>
</tr>
<tr>
<td>CAPITAL FUND</td>
<td>372,614,050</td>
</tr>
<tr>
<td>(Represented by Fixed Assets)</td>
<td></td>
</tr>
<tr>
<td>CAPITAL PROJECT FUND</td>
<td>20,823,556</td>
</tr>
<tr>
<td>GENERAL FUND</td>
<td>(10,211,189)</td>
</tr>
<tr>
<td>DESIGNATED/PROGRAMMES/OTHER FUNDS</td>
<td>122,924,478</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>414,250,895</td>
</tr>
</tbody>
</table>

| **APPLICATION OF FUNDS:** | | |
| FIXED ASSETS | | |
| GROSS BLOCK | 752,848,123 | 734,066,706 |
| LESS: DEPRECIATION | 380,234,073 | 349,142,978 |
| NET BLOCK | 372,614,050 | 384,923,728 |
| CAPITAL WORK IN PROGRESS | 15,622,699 | 15,222,421 |
| INVESTMENTS | 388,236,749 | 400,146,149 |
| CURRENT ASSETS: | | |
| CASH AND BANK BALANCES | 24,633,000 | 27,046,803 |
| AMOUNTS RECEIVABLES | 68,276,855 | 71,924,591 |
| LESS: CURRENT LIABILITIES: | | |
| AMOUNTS PAYABLE | 10,476,500 | 15,023,464 |
| NET CURRENT ASSETS | 77,372,209 | 69,974,785 |
| **TOTAL** | 414,250,895 | 444,166,222 |

**FINANCIAL POSITION AS AT DECEMBER 31, 2011**

(Figures – rupees in Lakhs)

**INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31ST DECEMBER 2011**

<table>
<thead>
<tr>
<th>Rupees</th>
<th>Rupees</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INCOME</strong></td>
<td></td>
</tr>
<tr>
<td>FOREIGN CONTRIBUTIONS</td>
<td>2,113,826</td>
</tr>
<tr>
<td>FOREIGN CONTRIBUTIONS TRANSFERRED FROM FUND</td>
<td>247,747,584</td>
</tr>
<tr>
<td>LOCAL CONTRIBUTIONS</td>
<td>192,858,349</td>
</tr>
<tr>
<td>LOCAL CONTRIBUTIONS TRANSFERRED FROM FUND</td>
<td>10,635,662</td>
</tr>
<tr>
<td>INTEREST</td>
<td>3,747,156</td>
</tr>
<tr>
<td>MISCELLANEOUS INCOME</td>
<td>1,624,134</td>
</tr>
<tr>
<td><strong>EXCESS OF EXPENDITURE OVER INCOME CARRIED TO GENERAL FUND</strong></td>
<td>88,734,184</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>457,460,895</td>
</tr>
</tbody>
</table>

| **EXPENDITURE** | | |
| PROGRAMME EXPENSES: | | |
| TREATMENT | 257,316,236 | 219,666,468 |
| DISEASE CONTROL / PUBLIC HEALTH PROGRAMMES | 16,374,996 | 16,811,468 |
| SNEHALAYA | 7,364,580 | 8,646,960 |
| LIVELIHOOD PROGRAMMES | 61,005,973 | 58,525,213 |
| COMMUNITY DEVELOPMENT PROGRAMMES | 30,560,098 | 31,978,831 |
| PREVENTION OF DISABILITIES | 12,812,395 | 15,165,601 |
| HEALTH PROMOTION & ADVOCACY | 19,239,375 | 17,170,054 |
| RESEARCH | 16,604,905 | 12,948,398 |
| GRANTS TO AIDED CENTRES | 17,504,464 | 25,627,984 |
| TRAINING / WORKSHOPS | 4,359,315 | 6,312,336 |
| EVALUATION | 1,099,042 | 1,828,564 |
| RESOURCE MOBILISATION EXPS | 3,837,817 | 4,172,634 |
| **ADMINISTRATIVE EXPENSES** | 99,462,699 | 67,514,113 |
| **TOTAL** | 457,460,895 | 486,374,624 |

**FINANCIAL RESULTS FOR THE YEAR ENDED 31 DECEMBER 2011**

(Figures – rupees in Lakhs)

**INCOME**

- Foreign Contributions: 2,113,826 (89.95%)
- Capital Fund (rep. Fixed Assets): 3,726,14 (89.95%)
- Capital Project Fund: 20,823 (5.03%)
- General Fund: (10,211) (-24.65%)
- Designated/Programmes/Other Funds: 122,924 (29.67%)

**EXPENDITURE**

- Gross Block: 752,848 (93.72%)
- Investments: 246,33 (5.95%)
- Cash & Bank: 682 (16.48%)
- Amounts Payable: -668.96 (-16.15%)
- Foreign Contributions: 2,498.62 (45.64%)
- Deficit: 887.34 (16.21%)
- Misc Income: 16.24 (0.30%)
- Interest: 37.47 (0.68%)
- Local Contributions: 175.04 (3.20%)

**SOURCES OF FUNDS**

- Capital Fund (incl. Fixed Assets): 526.24 (80.07%)
- Designated/Prop Fund: 120.04 (19.87%)
- General Fund: 103.11 (16.60%)
- Capital Project Fund: 208.23 (5.03%)

**APPLICATION OF FUNDS**

- Fixed Assets (incl. Cap. WIP): 800.07 (80.07%)
- Investments: 246.33 (5.95%)
- Cash & Bank: 448.04 (91.15%)
- Amounts Payable: -668.96 (-16.15%)

**WORKING RESULTS FOR THE YEAR 2011**

(Figures – rupees in Lakhs)

<table>
<thead>
<tr>
<th>INCOME</th>
<th>EXPENDITURE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL</strong></td>
<td>457,460,895</td>
</tr>
</tbody>
</table>
How to donate?
Cheques/DDs may be drawn in favour of
The Leprosy Mission Trust India, payable at New Delhi.