Cover Story

Leprosy: Why treatment needs to go beyond the cure
Cover Story

Leprosy: Why Treatment Needs To Go Beyond Cure

Article written by Geoff Prescott, Chief Executive, Lepra, UK

In the UK it costs on average £550 pcm more to live if you are disabled and prejudice remains quite common. Indeed many commentators have pointed out that the burden of austerity has disproportionately fallen on the disabled. As a Dad with a disabled son, I can personally confirm that in the “fifth richest country in the world”, prejudice, stigma and discrimination are thriving. These are the facts in a country with a plethora of anti-discriminatory laws and an active justice system to ensure they are upheld.

Upon my recent appointment with Lepra, I wondered when I travelled to India whether the situation would be better or worse for those affected by leprosy. Sadly though, after meeting patients, disabled people, community groups and staff I heard that India resembles the UK. There is more than enough prejudice and discrimination to go around it seems - though things are improving.
There is a great stigma attached to leprosy, leading people to be “cast out” from society, rejected by their families and friends, insulted and shamed. This inevitably leads to many avoiding treatment and fearing a diagnosis, even though there is a free cure. As a result, currently at least four million ex-leprosy patients live with a disability, largely due to a late diagnosis which increases the chances of severe disability. Some people with leprosy can experience paralysis in their hands and feet, causing clawed fingers and toes, desensitisation of their extremities leading to traumatic amputations, ulcers, gangrene and occasionally facial damage and blindness. All of this seemingly often invokes prejudice and fear, rather than empathy and compassion.

Leprosy is in a special category of disease though. It is frequently met with an absolute and unthinking prejudice and then a second discrimination towards the disability that leprosy can cause. To keep up the election jargon, “a double whammy.”

On my travels, I met Hassan whose life had been improved through reconstructive surgery at St Joseph’s Leprosy Centre. Leprosy had caused his hands to claw, leading to difficulty at home and losing his job. Worse, it identified him as someone affected by leprosy who was then rejected by his brothers and prevented his marriage going ahead. Treatment to destroy the disease had been successful, but the disability had left Hassan vulnerable to prejudice. Our surgeons were, however able to make significant improvements to his hands, restoring their appearance and most of their use. Hassan is now much happier; he is less subject to fear, suspicion and prejudice and those around him now have begun to accept that the disease was just bad luck, was barely infectious anyway and his treatment was successful.

For Lepra, our work, therefore, goes far beyond diagnosis and treatment. Last year we helped 594 other people living with serious leprosy related disabilities by facilitating their access to specialised centres focused on rehabilitation. One such centre is our St Joseph’s Leprosy Centre (SJLC) based in the Khargone district of Madhya Pradesh. This centre provides counselling, self-care services, ulcer and reaction management besides rehabilitative surgery. Interestingly, patients undergoing operations receive incentives compensating for their loss of wages. These enable them to pay for their journey, feed their families and so receive their life-changing treatment.

Fear and prejudice can be beaten and our work at St. Joseph’s is an example of that. Leaving India, I concluded that just like the UK, our societies have a long way to go to meet basic standards of disability care and to become free from prejudice. It was encouraging though to see that our work focusing beyond leprosy treatment to tackle prejudice and disability was enabling people to live a much better quality of life.

To find out more about how we’re changing lives with reconstructive surgery visit lepra.org.uk.

Project Activities

**Jharkhand**

**Sparsh - Tata Steel Inaugurates reconstructive surgery unit**

Tata Steel has dedicated a reconstructive surgery unit with a 10-bedded hospital for leprosy patients across the state (Jharkhand) to provide free treatment to those who have been disabled by leprosy. The reconstructive surgery unit was inaugurated by first lady of Tata steel, Mrs. Ruchi Narendran. They also distributed 2 Tricycles, 1 wheelchair and 2 crutches to needy persons.

SPARSH centre was graced by TATA dignitaries. In 2009, a disability care unit was started at SPARSH, Jamadoba which is providing OPD services to the needy. The services rendered are IEC, providing of specially designed protective footwear, physiotherapy, prevention of disability (POD), prevention of worsening disability (POWD) etc. This newly constructed hospital will support the patients with surgery with the help of dedicated surgeons. The RCS centre would provide pre and post-operative care. Earlier this surgery was done at Purulia Leprosy Mission Hospital, Purulia. A Reconstructive Surgery centre performs correction of deformities due to leprosy. A total of 13330 patients are being treated in OPD services, new leprosy case diagnosed-221, Ulcer treated for 437 patients, complication management done for 150 patients. Under AID and appliances distribution-44 tricycles, 37 wheelchairs, 135 crutches, 3889 protective footwear-distributed.
Awareness was the key to check the spread of the disease and activists of the organisation would visit different locations of the district to apprise students about leprosy. Awareness drives with the help of mobile education units of the society are also on the cards.

This reconstructive surgery unit will play a major role in leprosy eradication programme benefitting the patients from Jharkhand and Bihar, as the number of patients is more in these states. Already 10 patients have been admitted in the centre for RCS from Bhagalpur, Banka and Dhanbad districts of Bihar and Jharkhand respectively are likely to benefit from it with assistance of LEPRA society.

Case Study

Helping Others now

Chhabi Jani, son of Dhanu Jani, is 22 years old and is a resident of Hirmimunda village, Block: Tentulikhunti, Nabarangpur district Odisha State. He studied up to 7th class and stopped due to leprosy 12 years back. He is only one son of Dhanu. Since he looked very cute his parents named him Chhabi. His parents are having only one acre of seasonal cultivated land where they get 20 bags of paddy and for the rest of the year they are involved in daily labour works.

In 2009, Chhabi noticed some anesthetic patches over both the hands. He felt that it is some skin disease and it may disappear gradually. After two months he noticed another large patch over the arm and gradually oily shiny face was seen and his hand became anesthetic. During writing, he felt that his finger is slipping, and then he noticed the weakness of that finger. His family member took him to a Dishari (traditional healers) near Umarkote Kadaliukochha village and spent around Rs.2000/- for traditional herbal medicine for about six months, but couldn’t get any relief. Then he found his hand disabled. After three months, a health worker came to into contact and referred him to Tentulikhunti Hospital for confirmation. There the Medical Officer examined and registered him as a leprosy case MB. By that time already he developed disabilities in the hands. He took 12 months of MDT. After RFT, Nabarangpur NLEP staff referred him to Koraput Referral centre for physio care.

Chhabi came to Koralep, Koraput in 2010 and he stayed for four months for physio care and later stayed at Balarampur for one month. Koralep project extended its activities to Nabarangpur district and one CHP posted there was in regular contact with Chhabi and got him ready for RCS. Chhabi’s first operation was done in September 2013. After surgery he was able to perform his work. His second surgery was performed in 2015. During his stay at Koraput, the project facilitated for getting him a disability Certificate from CDMO Koraput. Chhabi also came to know about different schemes available for PAL. He applied for the disability pension and submitted to block authorities and he is getting pension of Rs 300/- every month as disability pension from social security’s scheme and bus concession pass.

He suffered clawing in both hands and was not able to do his day-to-day work properly, but after reconstructive surgery he is able to manage his day-to-day work, but his foot is anesthetic, so self-care is to be carried out regularly.

As he is the only son of his parents, they do not assign any work to him but now his age is 22 years and his income is zero. However due to project intervention Chhabi gets every month Rs 300/- Disability Pension and Bus Pass.

Before treatment, community members discriminated against him and he was having self-stigma so he could not attend any family or community functions but during and after RCS he came to meet different people affected by leprosy and was exposed to different places. So Chhabi could come out to enjoy in the society around him. He came to know that one can help and guide properly people with health problems. Thus he has referred 8 to 10 cases to CHC, DHH. The project also constituted a forum among PALs in March 2017, where he was selected as President for the block level forum. He wanted to do something for community. Now Chabbi is matured and is guiding newly affected persons and for RCS cases too. So he has become a well known person in that locality.
Madhya Pradesh

Training Programme

LEPRA Society state office, Bhopal, organised a two-day training programme on KOBO tool (mobile application) in implementing the baseline survey for its beneficiaries affected with leprosy and lymphatic filariasis.

The programme started with a warm welcome to all the participants, initial discussions were about the basic understanding of LF and leprosy. The purpose and importance of baseline was to assess the project performance, lead a road map for ensuring years of project. The participants were oriented on the questionnaire evolved in conducting the survey.

The State coordinator discussed the baseline survey plan with SANKALP team Panna and also on how to be implemented in the field adhering to timelines.

Charles’ visit to MP

Mr. Charles Bland, Chairman, Lepra visited an IPOD camp at Ajaygarh block, Taroni, village of Panna district to interact with beneficiaries and community members.

The Chief Executive introduced Charles to the affected community and their family members and briefed about the new project - SANKALP and its activities. In his address to the community, Mr. Charles raised the question of stigma and discrimination faced by them from their neighbours, villagers or family members. “Some members said they have” but others said at present such stigma is not there in the society.

The State Coordinator asked one lady “Rekha” to kindly explain the disease. Are you taking any treatment for this? She stated that she has been to Panna for treatment and the doctor suggested her for surgery, but as she could not take any decision she is back home with the same condition.

Three cases of leprosy and 11 cases of LF were available for self-care and morbidity management on LF and Leprosy. Seven (7) affected people’s family members also attended the camp. Two persons are new out of 14 affected persons.

During the camp, Hemant provided awareness on self-care, MDA programme, uses of shoe and cleaning of affected person to their family members and villagers. For morbidity management, kits were also provided to the beneficiaries. During the activities, the Project Manager and State Coordination facilitated both CEs in understanding the problems, stigma and discrimination by family members and society. Mr. Charles also enquired about the source of income and occupation and also wanted to know from the persons about their disease (LF+Leprosy), how long they have suffered it and the problems they face, and if the disease had effect on their work and if they feel alone in society etc. The affected persons answered and shared their problems. Mr. Charles interacted with a new patient Dilip, who was suffering from LF and was in Grade-3 and came for the first time to an IPOD camp. Mr. Charles asked why he came to the camp for the first time. Dilip said most of the time he is out of his village looking for employment wages as he is an unskilled labour. He added that he is affected for the last 20 years and has had lots of trouble in his life and also wasted a lot of money on treatment, but did not get any relief. He is happy to be present at the camp with other beneficiaries who were practicing morbidity management and getting relief. Another old patient Chanda Sen, shared her experience. An 80 year-old Chanda is affected from LF and came to the camp in November, 2016. Since then, she has been practicing self-care and taking medicine since December’16. By using Eva footwear, she got some relief and her swelling reduced by approximately 2 centimeters and now she feels better.
The Shoe technician took foot measurement at the camp for affected persons who learned how to manage his/her morbidity and use the prescribed footwear. Seven MCR & Eva footwear were distributed to old cases during the camp to make their lives easier.

In his discussions with government health officials, Charles briefed about LEPRA Society work in India and expressed the need to work together for betterment of affected persons and do qualitative work.

Mr. Rawat, DMO Panna, shared the issue of MDA programme stating that many people are not taking DEC medicine being provided by the government health volunteers it is too critical issue to deal with it. She then raised the points related to unawareness among people, vacant posts etc. The data available at the government was not reliable, no authentic data and also no plan for activity.

Dr. Sanjay Ahirwar, discusses the scenario of leprosy in the district and shared an example – that the district has 152 ANC DR cases but the actual figure is more as they are hidden, as we are not tracking those and present day to day cases are increasing.

The Nardaha village in Panna district reported 75 cases of LF contributing to 13% of total village population which resulted in failure of the MDA programme. As most of the people are not taking medicine it seems the affected persons are not properly counselled by volunteers. The ICMR team detects 146 cases of leprosy in Grade-2 and the cases with deformities are increasing.

LEPRA suggested sharing of monthly reports with the district officials, so that the department will be posted about the activities and the number of affected clients. The state coordinator highlighted our purpose of early detection to provide them early morbidity management and save them from disability. He also requested CMHO to share old leprosy data with the project staff to manage the morbidity of RFT cases.

The CMHO says elimination of leprosy is affected due to low resources and staff. For this reason leprosy survey work is getting affected.

There are altogether 20 cases affected from Leprosy, 5 affected people’s family members were also present with the affected persons and during the camp, Hemant, TO, provided awareness on self-care, MDA programme awareness, uses of shoe and cleaning to affected person. After completion of the patient’s registration, PT Aanknsha, gave a demo with an affected person and others managed morbidity with the help of Sankalp team members. Morbidity management kits are also provide to them and in all activities PM and State coordination facilitated in translating both the CEs. There was one lady who came with her relative who was affected with Leprosy and she was carrying with her a one-year girl child who was malnourished and Mr. Charles noticed and suggested to Sankalp team Panna to link the baby with NRC and, BC Shahnagar initiated the linkage the next day with NRC Shahnagar.

Mr. Charles asked the affected persons how they feel after wearing MCR and most who are wearing the MCR footwear which is provided by Sankalp Panna, said they are feeling better. After the IPOD camp both CEs thanked Sankalp team Panna and appreciated their work.

Meeting with State Forum Members
A small interactive session was held between State Forum (SKNS) and team UK to understand their role in upliftment of the people infected or affected by Leprosy, and the support they are receiving from LEPRA. This was more of an interaction to know more precisely their overviews.
SKNS started functioning in 2012 with support from LEPRA Society and APAL, the members were selected by the community to work towards the common goals. These committee members coordinate with colony committee and help individuals, addressing collective issues like cleanliness in the colony area, electricity issues etc.

In total 9 districts are connected to SKNS but they are not the part of SKNS, the district representatives of people affected with leprosy.

The grant being given by Lepra Society to SKNS supports their local expenses, office rent, monthly honorarium to chairman, travel cost etc.

LEPRA Society also provided orientation to these district level members & SKNS representatives on Leadership & Disability Act 2016 in January 2017 to have the knowledge of their rights. The support from CHAHA for the education and skill development helped to make them independent and confident.

APAL guides SKNS on its operations, advocacy, lobbying and updating members on International and National meetings. In their discussion they raised their voices to be a part of society with freedom from stigma and isolation. They also suggested regarding services they feel important for the people living outside the colonies which include treatment and counselling.

One of the major issues they face is the participation of women in the colony level institutions. The livelihood interventions done by SKNS is supported by Nippon Foundation which provides opportunities for People affected with Leprosy to undergo trainings, skill building and take up livelihood interventions in a group or individually.

**Andhra Pradesh**

**SANKALP - Mid -Term Evaluation**

SANKALP - a community-based project tackling leprosy and lymphatic filariasis, was initiated in November 2015 in 12 mandals of Krishna, Guntur and Prakasam districts, Andhra Pradesh. The main objective was to improve the health conditions of people affected by lymphatic filariasis and leprosy and to enhance their social and economic inclusion. It aims to support 600 leprosy and 2,500 lymphatic filariasis affected persons by the end of three years of project period.

A three-member team with experiences in their related field carried out the evaluation process. The villages and urban wards were considered based on the case load of a given village or ward thus randomly selecting every 10th village among 72 villages and urban towns. The first phase of the project was implemented in 6 out of 12 mandals for operational feasibility and the rest will be covered within the project completion period. The draft mid-term evaluation report with findings will be shared shortly.

**Odisha**

**SANKALP - Mid -Term Evaluation**

SANKALP “Tackling Lymphatic Filariasis and Leprosy” project is implemented in Puri and Nayagarh districts of Odisha, since November 2015, spread across 172 gram panchayats in seven blocks with a population of 1 million. The project aims for improved availability and access of people to lymphatic filariasis and leprosy-related services in a combined manner with emphasis to women and children. The project activities were executed in collaboration
with National Leprosy Eradication Programme and National Vector Borne Disease Control Programme. A mid-term evaluation was undertaken through a combination of processes including a desk study, selected site visits and interviews of stakeholders, to assess the project overall performance. The observations of evaluation team were encouraging with few technical issues which are unlikely to be resolved by the project team. The project coordination with government officials at district levels found satisfactory, who insisted to run the project in high endemic blocks other than the selected project seven blocks. The project interventions were very effective in increasing the awareness of leprosy and lymphatic filariasis among general population.

LSHO - Human Resource

Mr. Veerendra Dubey has joined LEPRAs as a Project Manager, Sankalp project, Panna with effect from 01 July 2017. A qualified social worker with 15 years of work experience and a masters degree in Sociology from Chitrakoot University and LLB from Dr Hari Singh Gour, University, Sagar. He was earlier associated with PHFI, Bikaner, Rajasthan.

Things you should know...

Disability inclusion: How to overcome the barriers to a career in global development

Across all industries, people with disabilities can face physical and social barriers to employment. The development sector can, however, be particularly challenging, explains Dylan Hedtler-Gaudette, advocacy and policy researcher for the National Federation of the Blind. While he has always been up front in telling potential employers that he is a blind person, Hedtler-Gaudette acknowledges that doing so can result in fewer call backs. “Misperceptions about the capacity and capabilities of people with all kinds of disabilities” are commonplace, Hedtler-Gaudette says. “In the development space, it’s even more pertinent.” He notes that there is an “attitude that people with disabilities can’t be out in the field or they can’t do certain things,” but he points out that these assumptions are often false.

Despite many employers referencing disability and inclusion policies, often mandated by law, there is a lack of job opportunities for people with disabilities. Legislation is one thing but the practicalities of it are another, explains Mosharraf Hossain, director of global policy, influencing and research with ADD International.

One of the main challenges for the disabled community is that “the disability cause tends to be looked at as an individual issue” and it lacks the media recognition that other causes receive, according to Robin Marcato, management analyst at U.S. Agency for International Development Office of Information General. People with disabilities or mental health issues also face issues in advocating for disability issues because they are “very often terrified to speak about accessibility; they don’t want to be targeted,” she says.
“Art from the Heart” – an art exhibition conceptualised as a fund-raiser for LEPRA Society in association with Daira Art Gallery and Chitramayee, State Art Gallery was held from April 28 to May 7 at State Art Gallery, Madhapur, Hyderabad. This art show was inaugurated by Amala Akkineni, actor-activist and founder of Blue Cross of Andhra Pradesh. About 75 paintings of well-known artists of the twin cities were on display. The inauguration was well attended. Mr. B V Papa Rao, Advisor, Government of Telangana also attended the event, which received press and media coverage and also helped mobilise funds for the people affected by leprosy!