2021
Annual Report

Lok Seva Sangam
Since 1976 serving the poor

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2021

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2021 ANNUAL REPORT

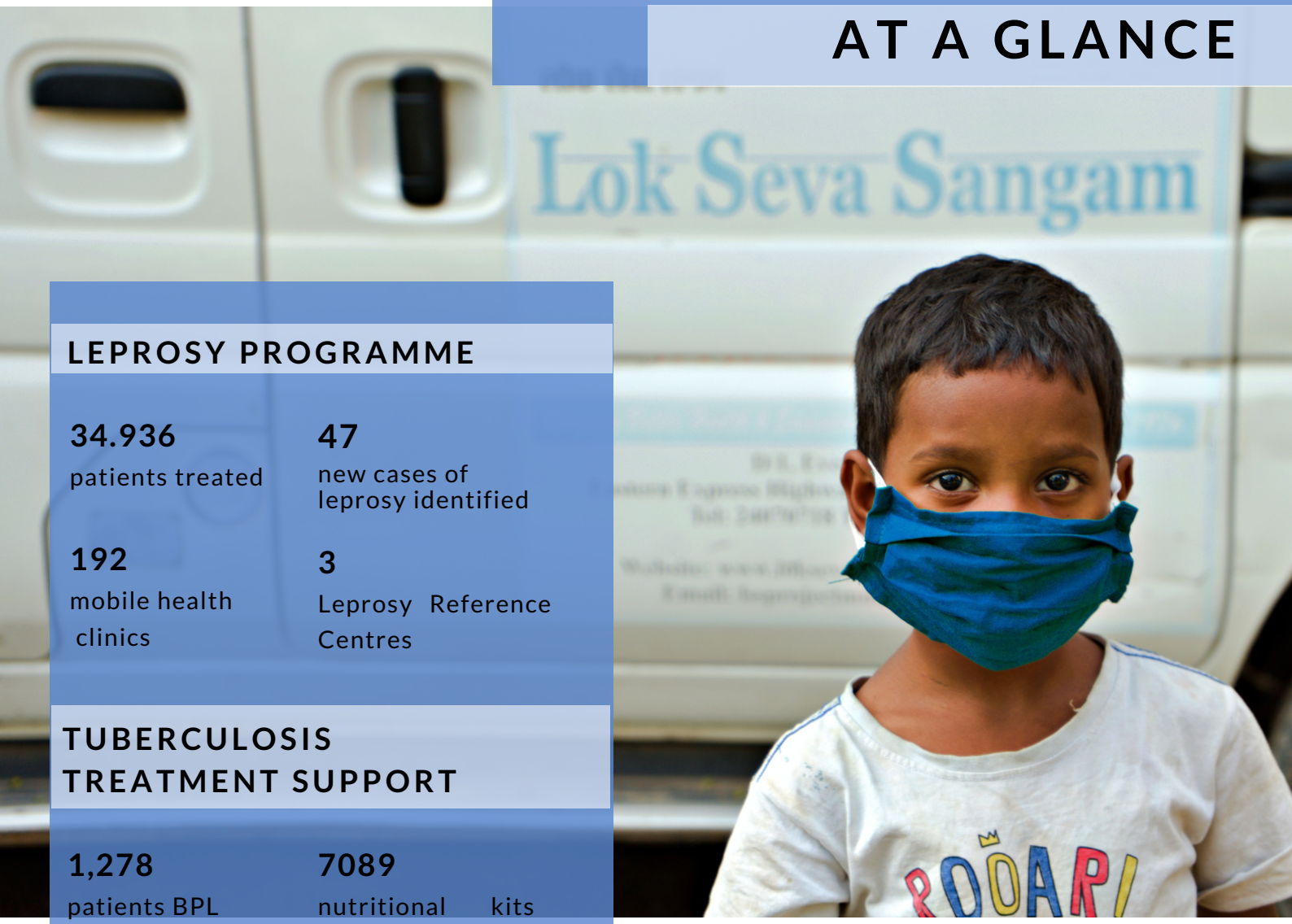
EXECUTIVE SUMMARY

Grassroots work in the development sector is something crazy. At the community level, everything is difficult to predict, patients arrive late, children lose their books in the floods and documents get eaten by the rats. It is crazy also because resources are insufficient, salaries are not great and we receive double scrutiny from the government. Yet, when we see the smile on the faces of the kids; when we see the relief and gratitude in the words of the patient who feels his or her life was saved, then it is all worth it. For these moments of ineffable beauty, we keep doing it. It is crazy, we know.

This report will take you through the activities and impact of LSS during the year 2021. Starting with a glance at the numbers of the social impact of all the 4 programmes, it will then present a summary of the organization's history and location of activity. The next session will be a presentation on the leprosy programme, the first one to be started, now 46 years ago. It will be followed by a summary of the TB Treatment Support and the Education programmes. Finally, a brief presentation of the Family Development Programme will conclude.

We believe that a better world is possible, where inequality is reduced and all have access to the basic facilities of quality health and education. The work done this year was just a drop in an ocean of needs, but it made a great difference in the lives of those who we could reach. An not only, but to do this work transforms also our lives, each one of us, managers, project coordinators and field staff. For this reason all of us are pleased to go to the field, meet the people we work with and learn from their struggles and their unwavering hope. At the end of the day, we often find out that the true beneficiaries are ourselves.

2021
AT A GLANCE



LEPROSY PROGRAMME

34.936
patients treated

47
new cases of leprosy identified

192
mobile health clinics

3
Leprosy Reference Centres

TUBERCULOSIS TREATMENT SUPPORT

1,278
patients BPL being followed

7089
nutritional kits dispensed

90%
success rate of treatment for drug sensitive patients

14,148
home visits done

EDUCATIONAL PROGRAMME

113
students being followed

55%
reduction in the rate of Moderate malnutrition (MAM)

48
children engaged in capoeira

FAMILY DEVELOPMENT AND WOMEN EMPOWERMENT

853??
Home visits

X
participants at awareness meetings

x
families being followed

X
issues being addressed

OUR HISTORY

Fr. Carlo Torani (PIME), was an Italian that came to India in 1969. In those years, the Prevalence Rate of Leprosy was around 57.60 cases every 10 thousand population (100x higher than nowadays[1]). This means that there were more than 3 million cases, and people with the characteristic deformity could be found by the hundreds under the bridges and on the sidewalks.

Sr. Damiana Tansini (MSI) had started a small dispensary to treat these patients in a slum in Ville Parle. She invited fr. Carlo to the Christmas mass with the Tamilian Catholics of the slum. There, under the stars of a clear sky, fr. Carlo contemplated the group of people gathered around the bent wooden table and the dim light: they were poor, sick, marginalized. A thought came to him like a shooting star: If Jesus was to be born today, he would choose a place like this. That was the inspiration he needed. The following year he enrolled in TISS to study MSW on Community Organization and, after that, we went to live in a slum in Janata Colony. In 1974, a dispensary was opened in Chunabatti and, on 5th February 1976, the NGO was registered with the name of Lok Seva Sangam.

The objective was clear from the beginning: through health and education, work for the restitution of the dignity of the most marginalized, especially the leprosy patients. The process should be systematic, scientific, and measurable. Being the first civil organization of this kind in Mumbai, LSS received the mandate from the municipality to be responsible for the L and M wards. In this area, we should identify new cases, conduct surveys and awareness campaigns, and establish laboratories to do the bacteriological test, ascertaining new cases. LSS quickly reached 60 staff supported by Toriani's friends and relatives abroad. In 1980, LSS was running 33 skin clinics in M and L wards. In 1982, the Multidrug Therapy (MDT) was introduced, and the cases started to decline.

Nevertheless, many patients with deformities were rejected by family members and employers. They had no place to go. For this reason, in 1984, Swarg Dwar was founded. It is an ashram where patients from any caste, religion or origin could stay, practice their faith, work in the fields and live peacefully.

[1] https://dghs.gov.in/content/1349_3_NationalLeprosyEradicationProgramme.aspx

A similar situation was faced by the children of the leprosy patients. They were suffering from stigma and marginalization and often were not accepted in many schools. For this reason, under the guidance and sensibility of sr. Luigina Marchesi, in 1986, LSS started a small school in Bainganwaadi, and later, in Chunabhatti and Cheeta Camp.

In 2004, with the support of Inter Aide, LSS started a programme on TB identification and treatment. Initially, we were responsible to establish laboratories that would do the sputum test to identify cases. Gradually, this function was assumed by the government, as well as the provision of medicines, which originally, we were also doing. LSS gradually moved to a Treatment support programme, working in synergy with the government that provides us with the list of the new cases. We conduct weekly visits to each patient ensuring treatment adherence, correct nutrition, and habit change.

In 2015, under the guidance of Inter Aide, LSS started the new Family Development Programme (FDP), working with counselling and women empowerment. With the integration of leprosy in the general health system, LSS's services in these fields were reduced, and from 60 staff we now have 15. Then, it was FDP and TB who took the lead, adding other 65 field staff to the organization.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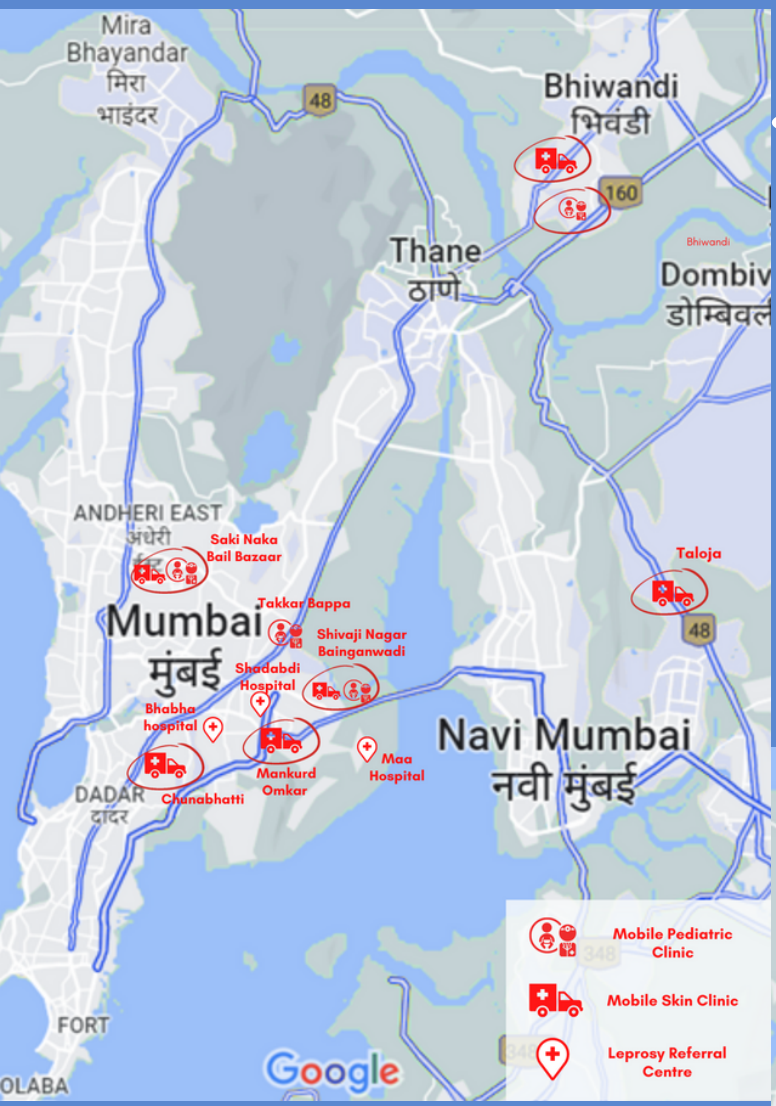
WHERE WE WORK

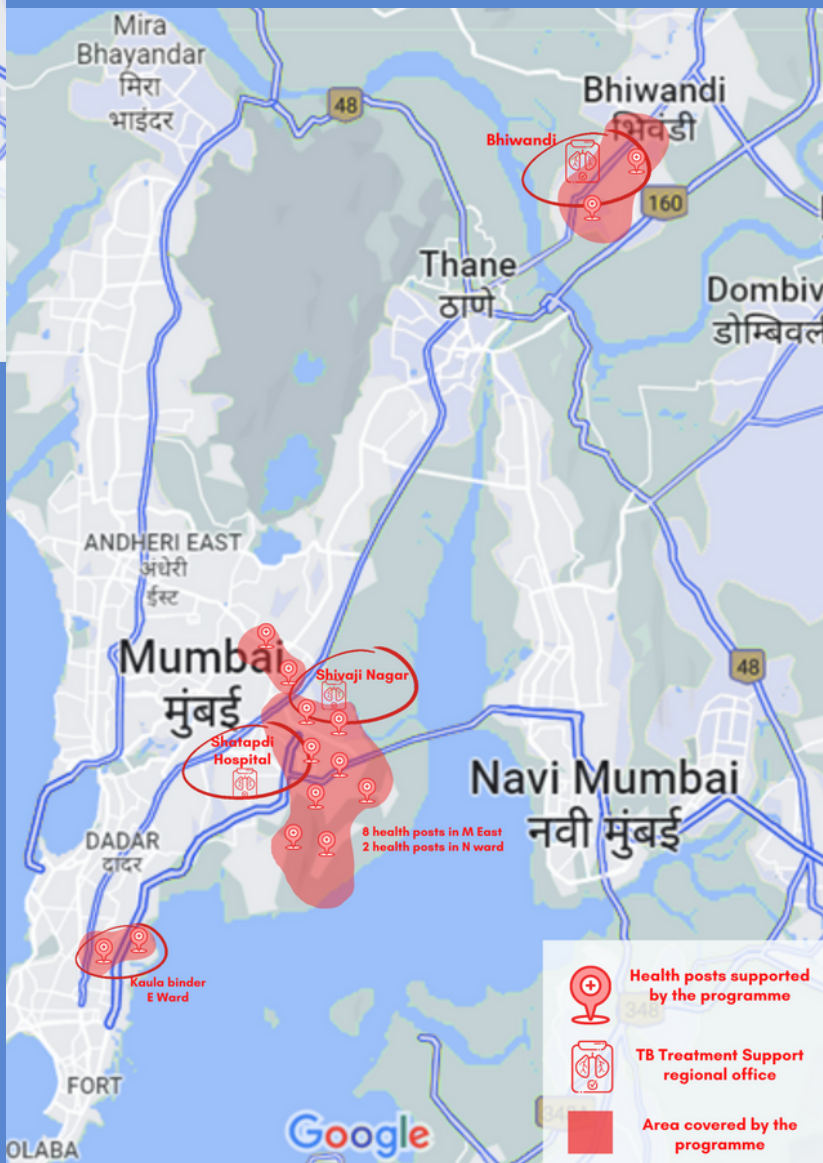


The Leprosy programme

- 15 Locations for Mobile skin clinics
- 9 locations for Pediatric clinics
- 3 LRC

TB Treatment Support

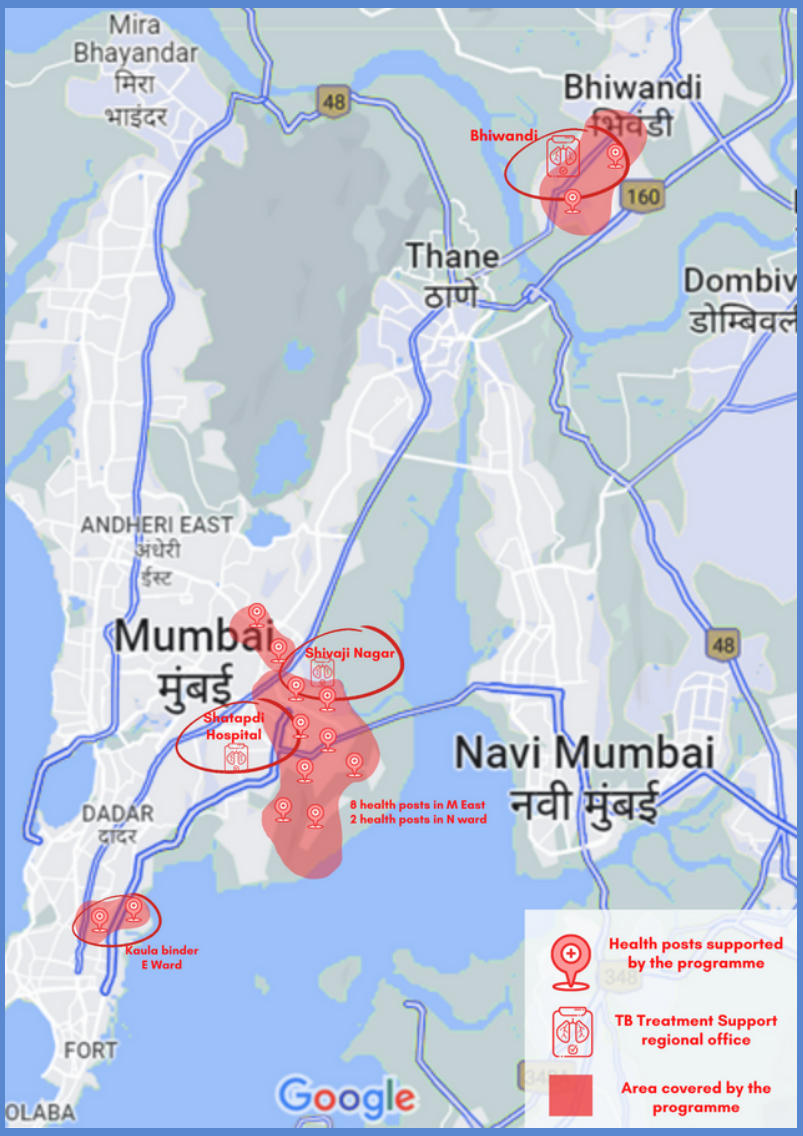
- 12 health posts supported in Mumbai
- 2 health posts in Bhiwandi
- 3 field offices



LSS लोक सेवा संगम

WHERE WE WORK

Family Development Programme



Bhiwandi

Mumbai

Jaipur

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THE LEPROSY PROGRAMME

In 2020, there were 1,27,558 new cases of leprosy in the world, 56% of which are in India. To reach the elimination of leprosy, the awareness of the population and early diagnosis are the key players.

In 2021, the World Health Organization has launched the campaign "Towards Zero Leprosy - Global Leprosy (Hansen's Disease) Strategy 2021-2030", in alignment with UN's SDGs 3 and 11 - Good health, well-being and reduced inequalities.
Despite the international attention, the cases in India registered in India were 73,108, representing 57,3% of all the cases in the world, a percentage that has not been decreasing over the years (WHO, 2022).

Funding and policy
In 2005, the government declared the elimination of leprosy as a health problem, which means the national average of cases fell below 1 per 10,000. Since then, funding for the National Leprosy Elimination Programme (NLEP) has been progressively reduced, chocking the system that prevented the disease to spread. The risk is of a silent upsurge from high endemicity pockets, without proper detection and diagnosis.

If the majority of the cases were detected early, we would expect the percentage of cases with deformity (Grate II cases) to drop close to zero. Yet, in Mumbai, the Grade II cases are more than 18%, and child cases are 16%.

Our initiatives

To prevent the disease from spreading, it is indispensable to reach the marginalized strata of the society, where the pockets of high endemicity are located. To prevent deformities and handicaps, an early diagnosis is equally important. To achieve this goal we use a multidimensional strategy:

- Mobile dermatological clinics offer medical visits and treatment at affordable prices in slum areas and zone of marginalized communities.
- Identified cases are followed to ensure continuity of treatment and good nourishment conditions
- Patients that are below the poverty line receive further support
- Door to door surveys are organized occasionally to search for new cases

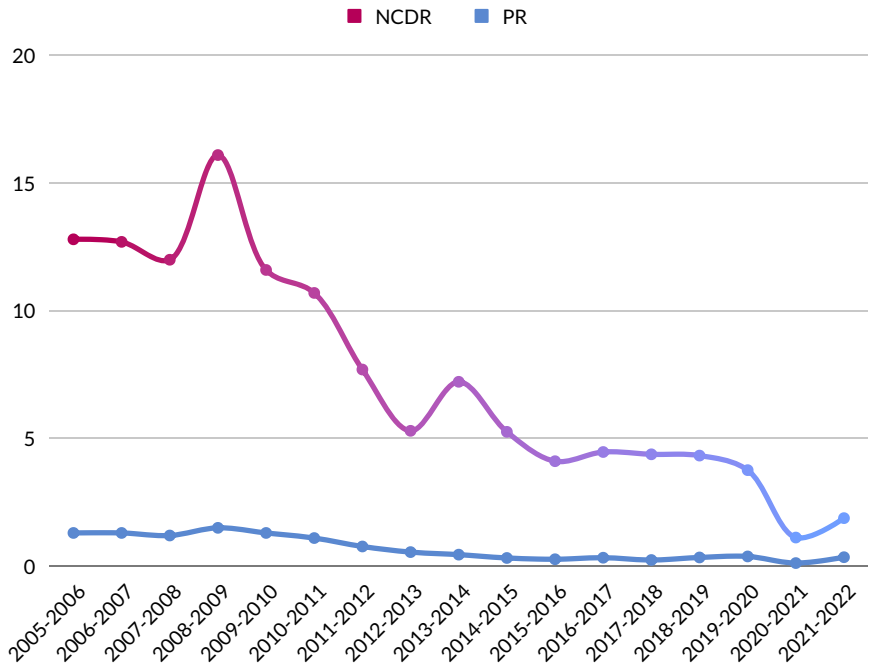
LSS has the mandate from the municipal commission to survey and follow the cases in Mumbai, M/East, M/West and L Wards. The prevalence rate of leprosy from over 15 per 10,000 of the population(before 2005) to just 0.09 in 2020.

School surveys

In the area assigned to LSS, 134 schools are present. In 2021, our staff visited 80% of these schools, raising awareness about the disease and doing active identification. Among the children and youth, 6 new cases were found.

TRENDS IN THE NUMBER OF CASES

The trends of Prevalence Rate (PR) and annual New Case Detection (NCDR) are indicated in the graph below:



This chart reveals a reduction in the total number of cases detected in the NGO's area of activity. After active surveillance and close follow-up, during the years the NCDR in our area fell to half of national average.

NCDR

2.44	4.74
AVERAGE IN OUR AREA	NATIONAL AVERAGE

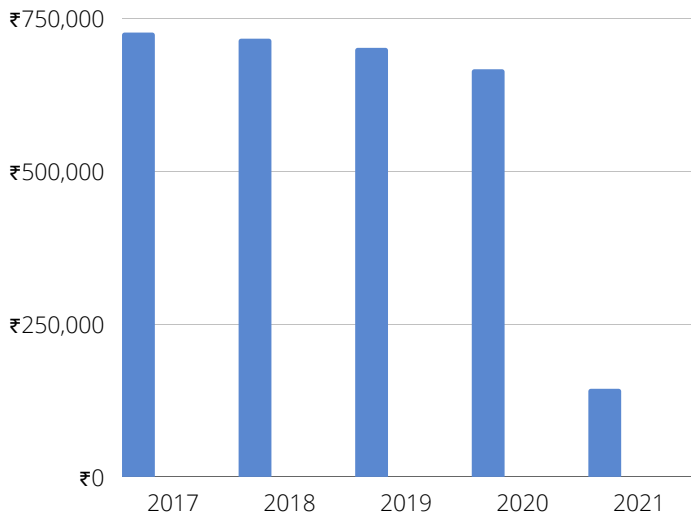
Despite this good news, it is too early to celebrate. A drop in the detection rate can be associated with less diligent surveillance. This explains the steep reduction in 2020, when lockdown restrictions curbed active detection. During the last two years, the pandemic constraints prevented surveys and outreach activities, causing a reduction in case detection of 56% at the national level and 29% in our reality.

If the detection system was fully efficient and the eradication was close, we would expect low rates of child infection, as well as less patients with deformities (Grade II patients, that indicates an advanced case left untreated for years).
The trend show that this cases are still high, except for 2020, due to lockdown. The percentage of Grade II cases, specially, have been rising.

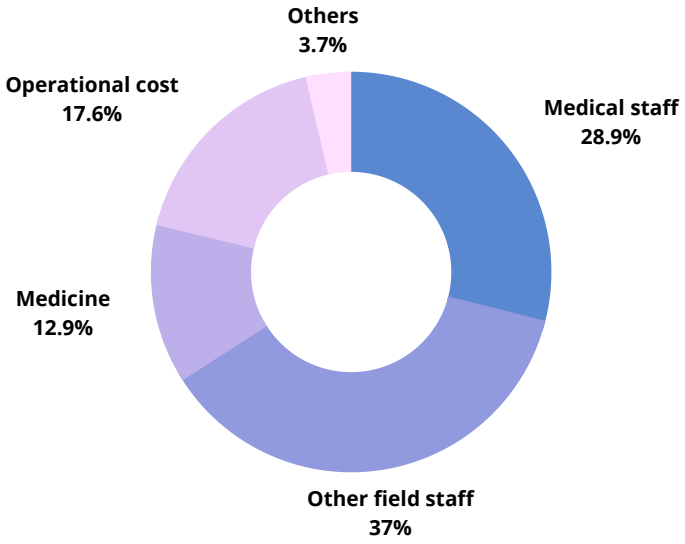
BUDGET CONSTRAINS

Despite the importance of prevention and early treatment of Leprosy, the funds from NLEP have decreased progressively over the years, as the following graphic shows. The prognostic is of further reduction, making ours and the work of other partner organizations unfeasible.

Amount received from NLEP



Expenses



The annual cost of the project is approximately INR 29.17 lakh. This amount has been reduced over the years because of the shortage of funds, in a way that is becoming difficult to survey and treat a population of 25 lakh.

The situation is such that non-profit organizations have been reducing their presence and activity. Unfortunately, we have been seeing that no one is filling the gap left by them.

Our aim is to support the patient in overcoming barriers to reach a successful treatment and save lives

TUBERCULOSIS TREATMENT SUPPORT PROGRAMME

A total of 1.5 million people died from TB in 2020. Worldwide, TB is the 13th leading cause of death and the second leading infectious killer after COVID-19. Despite being treatable and curable, TB remains a health security threat. Only about one in three people with drug-resistant TB accessed treatment, being a problem related to social marginalization.

United Nations' SDG Target 3.3 includes ending the TB epidemic by 2030. The goals are a 90% reduction in the number of TB deaths and an 80% reduction in the TB incidence rate (new cases per 100 000 population per year). To reach these targets, India is a key player. In 2020, India accounted for 26% of the incident TB cases across the globe. The country's incidence rate of 192 cases per 100,000 population, is 38% above the world's average (WHO, 2021).

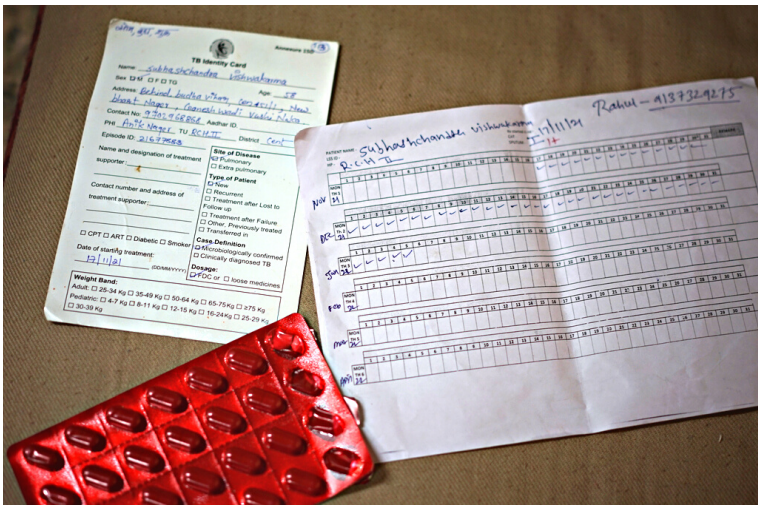
In India, the Revised National TB Control Programme, today named National Tuberculosis Elimination Programme (NTEP) established a framework explicitly calling the engagement of all stakeholders, including the national and state governments, development partners, civil society organizations, international agencies, research institutions and private sector. Indeed, socio-economic factors play a decisive role in the spreading of the disease, with malnutrition, lack of information, and migration playing a key role in the low treatment adherence.

Our initiative

LSS maintains a treatment support programme where a social worker will visit weekly the patients undergoing treatment, especially those in the condition of poverty or that have special difficulties with the treatment.

Objectives

- To support the patient to overcome barriers to a successful treatment.
- Improve treatment adherence and manage treatment interruption
- Detect and manage/refer drug- side effects
- Get follow up/final sputum test done

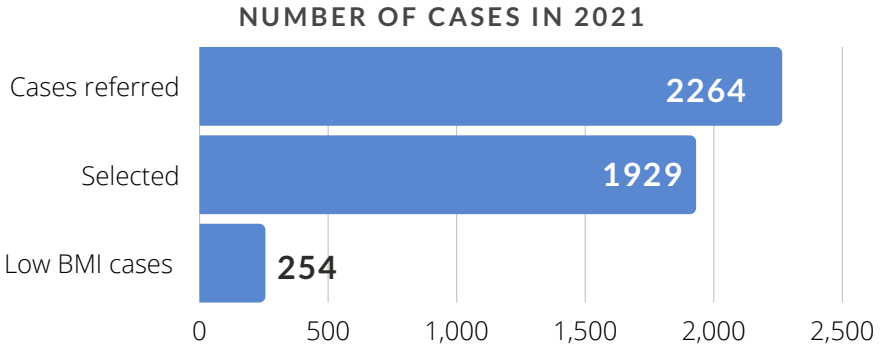


The confirmed cases are listed by the PHC that communicates with the social worker in charge of that area. The patients are then contacted for an initial visit, in which a Poverty Assessment Tool is applied to select the families with the greatest need. In 2021, 2264 cases were referred and 1929 were selected to receive treatment support. Among these, 254 had a low Body Mass Index (BMI<15) and were selected to receive Nutritional Support (see "stories of change" ahead).

Patients will receive a weekly visit, with guidance on the use of FDC, weight monitoring and the control if the patient is taking the drugs as advised. One of the most important aspects of the visits is the education and counselling because, in many cases, the lack of information on the treatment and its side effects is the main cause of treatment failure.

TB TRENDS AND NUMBERS

The number of cases referred by PHCs in our area, the cases selected according to the poverty standard, and the cases with low Body Mass that were followed with Nutritional Support are displayed in the graph below:



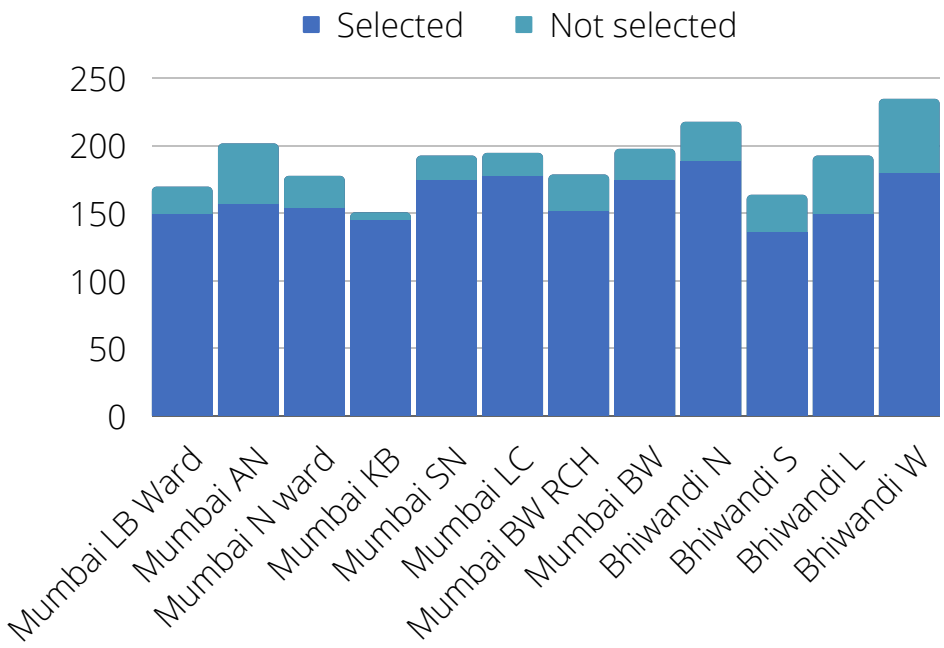
The following chart presents the number of selected cases (light blue) and the number of non-selected cases in each of the areas where the programme is being conducted.

The selected cases are those with PAT scores above 35, indicating better livelihood and housing conditions.

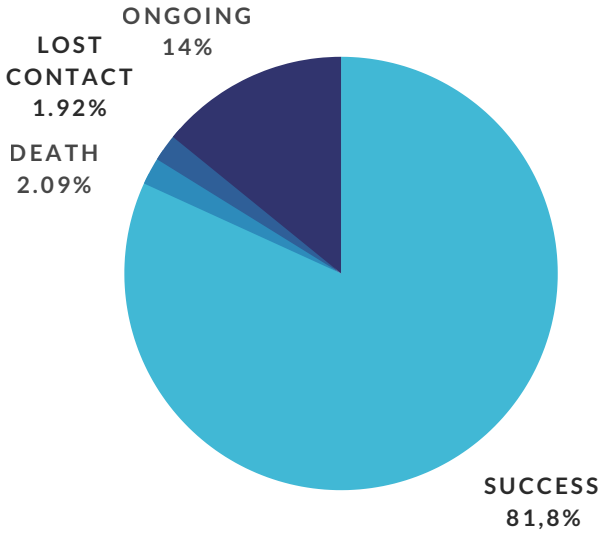
The PAT form evaluates income, health, good, amenities, housing, etc.

AVERAGE SELECTION RATE OF PATIENTS

85.5%



The outcome of the treatment is displayed in the pie chart below.



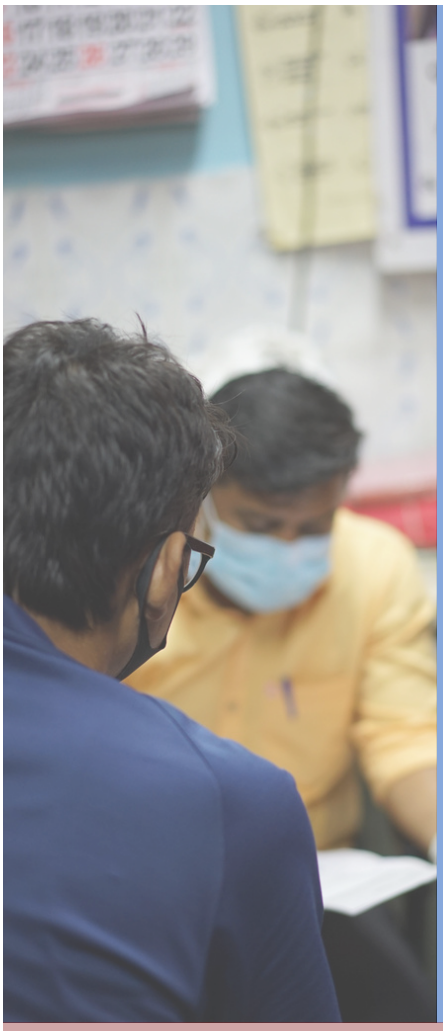
Of the total phase-out patients, both Drug-Sensitive and Drug-Resistant, 81,8 % had a successful outcome, meaning that they were bacteriologically confirmed (microscopy, culture or molecular test) and who completed treatment.

SUCCESS RATE*

69%	72%	81%
CHEMBUR	GOVANDI	LSS

*Cfr. GoI (2019) NTEP Annual report, p.183ss

STORIES OF CHANGE



Kartik* is a skilled carpenter from Vashi Naka, a densely populated area of Mumbai created by the Slum Redevelopment programme. Removing thousands of families from their shacks, the municipality built eight-storey edifices, rude and packed since inception. Kartik's income, above the average of the area, used to give him a satisfactory life for his family. He is 33 years old and has 3 kids, one girl of 9 and two boys, one of 6 and another of 4.

One day Kartik noticed while sanding a wooden table, that he had lost the sensibility in two of his fingers. Like most other slum dwellers would do, he just ignored it. There are other priorities in life – assuring a meal for example. But some days later, his whole arm got swollen. When he finally decided to go to the hospital, he was unable to stretch his fingers, making him unable to work. His hand was assuming a claw-like shape, typical of the disease he had: leprosy.

At Shatabdi hospital, he was sent to a Leprosy Referal Centre run by LSS. Initially, he would ask himself questions like "why me?" and how did he get it, since he was healthy and young. But soon after taking the medicines, the swelling reduced and movements improved. Unlike many others, he was exceptionally assiduous to the physiotherapy sessions, offered by LSS, so that the atrophy in his hand disappeared. Being a grade I patient, he was able to revert to Grade 0, being cured and without sequelae.

Suman* is 32 years old and has been married for 9 years. Having no children, he lives in a joint family with the brother, his wife and 4 kids. He is a tailor, working in one of the hundred small garment manufacture plants hidden in the small alleys of Shivaji Nagar. In 2018 he started having a cough, a symptom that increased to become continuous and distressing.

At the local hospital, he was diagnosed with Tuberculosis and referred to the local health post for follow up. He started taking the Multi-drug treatment, but the weakness and loss of appetite were withstanding. He was unable to eat and reached 30kg, point when he started asking himself if he would survive. He also moved out of his brother's place, to avoid exposing his baby and wife.

Enrolled at the LSS TB Treatment Support programme, he received weekly visits from a social worker, offering him counselling and orientation medicine use and alimentation. His weight was monitored closely and he started receiving nutritional support. He tells that after starting taking the powder milk reinforced with protein, he started feeling better, his appetite returned, his motivation as well. He started having four meals a day, he says among laughter, more than his mason friends. He says the frequent visits and phone calls from the social worker were important, motivated him to improve. Today he is 70kgs, with a fit and sound body structure, happy to talk about his progress and to motivate others to face this disease.

*names changed for privacy

THE EDUCATIONAL PROGRAMME

The challenges of education in post covid era are felt in a special way by marginalized communities. We have been trying to remediate the closure of schools by providing the students with mobile devices and internet connection for online tuitions.

By the end of 2021, the schools in Mumbai summed more than 600 days of closure. Studies show that for every school day missed projects to twice the learning loss for children: those that attended just a few years of school risk retaining almost nothing after this long gap.

According to the Annual Status of Education Report (ASER) survey 2021, as a result of the covid impact, there has been a shift from private to government schools, and an increase in child marriage and in school drop-outs. It has reported a growing dependency on private tuition classes — and a stark digital divide, which carries the risk of severely affecting the learning abilities of students. If 67% of the families report having a smartphone, only 27% of the children have access at all times.

The situation our children

The crisis is most felt in the marginalized areas. Most of our students live with their families in a single-room home, and the space for learning has to be shared with siblings from other classes, eventually with a mother cooking and a baby crying. Most of the families report having only one smartphone phone, that has to be shared

OUR ACTIVITIES

Seeing the difficulty faced by our patients to keep their children in school due to stigma or economic constraints, LSS decided to start the educational programme. It is designed as a support system, working in synergy with the local schools. The younger children receive English Medium education in our preschool, and then they are followed by quality tuitions during school ages. Extracurricular and sportive activities add to a wholistic formation.

PRE-PRIMARY

Present in locations where children are exposed to risk and vulnerability, LSS has 3 kindergartens that offer a safety environment, with education in English and a mid-day meal. The quality of the services is acknowledged by the community, in such a way that the waiting list doubles the number of post our community centre can receive.

TUTORIAL STUDENTS

When our kids reach the age of formal education, they will go to the school according to their language group. They continue to be part of LSS family, coming daily for tuition classes according to their age and language group.
By complementing the formal school education we can reach a greater number of students and follow their development across the years.

EXTRA-CURRICULAR

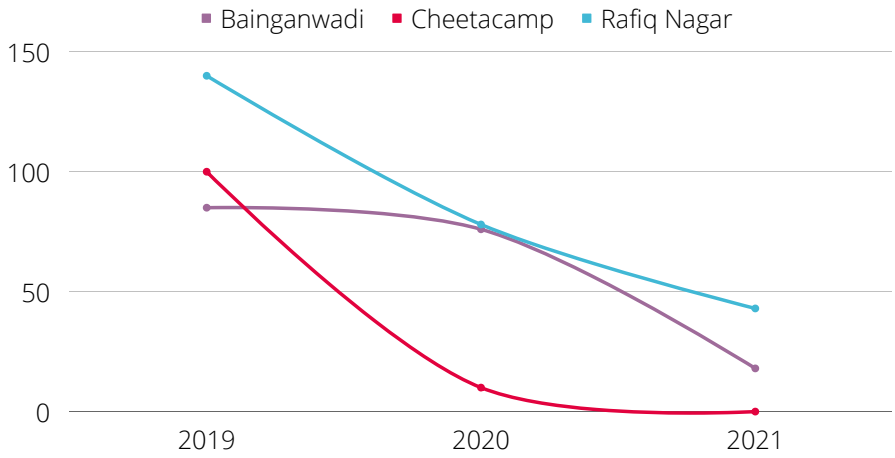
Dancing, drama and craft-work are part of the activities at the community centres, adding joy to the beautiful smiles of our kids.

A special note to our CAPOEIRA group, the Brazilian martial art that keeps our kids in good health while teaching them discipline rhythm.

PRE-PRIMARY SCHOOL

Following the directives of the municipal corporation, during the year the kindergarten was closed to face to face interactions. The online modality is particularly difficult for young kinds, and we saw the attendance reducing during the year, and the centre at Cheeta Camp was closed. But in 2022, we expect to see our kinds in full force and great numbers!

EVOLUTION IN THE NUMBER OF STUDENTS OF THE BALWADI



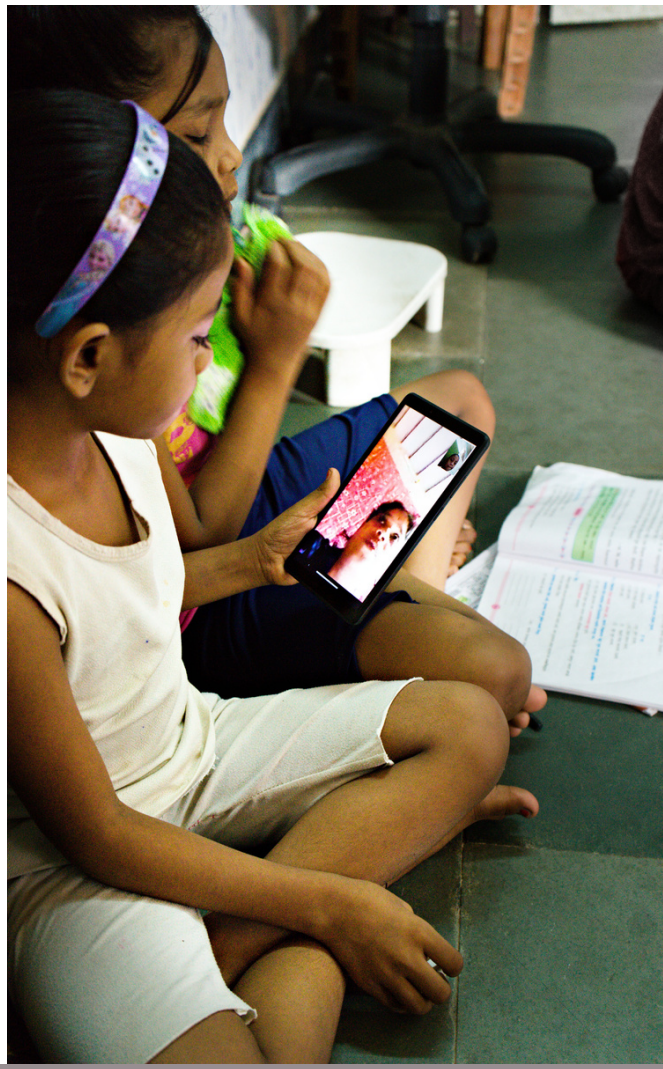
BALWADI LOCATION	NUMBER OF STUDENTS BY END 2021
Bainganwadi	32
Cheetacamp	-
Rafi Nagar	43
TOTAL	**75**

TUTORIAL STUDENTS

LOCATION	STANDARD	NUMBER OF STUDENTS BY END 2021	BOYS	GIRLS	TIME
Bainganwadi	1st to 4th	26	12	14	Online study
	5th to 10th	23	12	11	Online study
	Total	49	24	25	------
Rafi Nagar	1st	9	2	7	Online study
	6th -7th Hindi med.	15	9	6	10:30am -4:00pm
	6th-7th Urdu med.	14	9	5	10:30am -4:00pm
	Total	38	20	18	------

To facilitate the online tuitions for the students, LSS acquired 15 tablets and earphones. The students who could not attend the tuitions from home were invited to come to the centre, in small groups, following the SOP, to attend their class.

On **July 9th**, a parents-teachers meeting was conducted by the Programme coordinator, Seema Patil. It was an opportunity to understand the families' difficulties and to reinforce the importance of the student's attendence even during online classes.



EXTRA CURRICULAR ACTIVITIES

Capoeira

Capoeira is a Brazilian martial art practiced by enslaved Africans brought to Brazil since the 16th century. Forbidden to practice for war, the fighting techniques were disguised as a dance, developing beautiful movements with kicks and acrobatics at the rhythm of musical instruments.

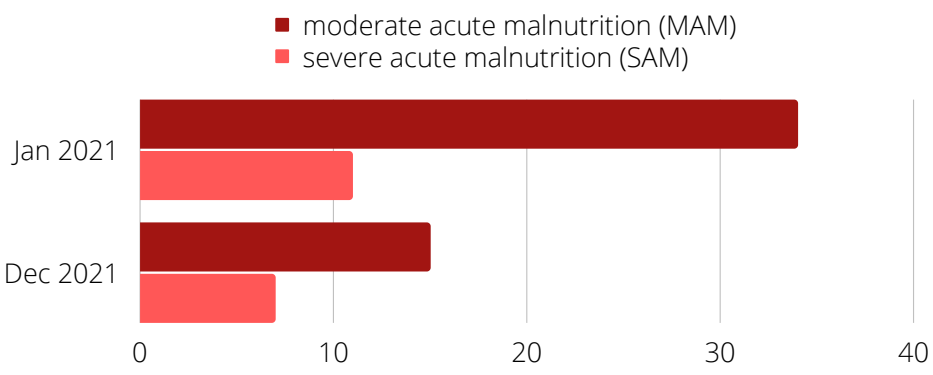
In India, Capoeira has been taking ground recently, with several centres being open all over the country. LSS received the first group in Mumbai, with the Brazilian master Chicote coming to form a group of students in 2010. Since then, our "Familia de Ouro" (golden family) has been teaching values and discipline to the kids of Bainganwadi

CAPOEIRA CLASSES

AGE GROUP	NUMBER OF STUDENTS
5 to 8 years-old	18
9 to 18 years-old	20
Above 18 year-old	10
TOTAL	**48**

Malnourishment control and intervention

The students' body mass index (BMI) was measured and 125 were identified as having a low rate and started being followed with monthly measurement, fortified food packets given and nutritional reeducation.



FAMILY DEVELOPMENT PROGRAMME

Inter Aide started implementing Family Development Programmes in the 80's in deprived urban areas in Brazil, and later in the Philippines, in Madagascar and in India. The family development method has evolved throughout the years, based on the experimentation of new innovative interventions aiming at responding to the beneficiaries' identified and expressed needs. From April 2013, LSS signed a MoU with Inter Aide. Since then, FDP came to be one of the LSS's programme. At the present, FDP programmed is carried out into locations: 1. Mankhurd (Shanti Nagar, Banjar Wada, Patra Chawl, Indira Nagar and Bhim Nagar); 2. Bhiwandi (Mansurabad, Gaytri Nagar, New Aazad Nagar, Fatima Nagar, Ram Nagar and Ummat Nagar).

Programme's objectives

The general objective of Family Development programs is to alleviate poverty in the most deprived urban communities in intermediate and developing countries, by facilitating sustainable access of the poorest to health, education, family welfare and social services. More specifically, the aim of Family Development programmes is to bridge the gap between the extremely poor and the available organisations providing health, family planning, education, social and economic services in a sustainable way.

Our activities

Home Visits – A individual approach of families: Family Development Workers (FDWs) approach families directly, going to their homes so as to establish a relationship, inform them about the program, and offer them to benefit from weekly home visits as well as other activities.

Awareness Meeting - Informative sessions: To cater to the common issue and area-specific need informative sessions are held at the community level. These AMs are organized by the respective organization. The sessions are taken within the project area. Depending on the need and topic the team decides to have an internal or external Resource Person.

Guidance Centre – A Counselling Centre: not only the families followed up through home visits, the centre is where the inhabitants can get proper information on various social issues, referrals to external agencies and counselling services. It is also a place where the FDP staff can have confidential counselling sessions with the beneficiaries who benefit from home-based follow-up or not.

STORIES OF CHANGE

Changing people's behaviours or transforming oppressive relations is a really challenging task, maybe more difficult than simply providing goods. But clothes, food and even a new house will not solve the problem of a person suffocated under unbalanced relationships.

Jaya* was 28 years old and was living in a slum area in Mumbai with her husband, her mother-in-law, sister-in-law and her son of 1.5 years old. Her sister-in-law, Meena, was very dominating and would control all the family members. She would accuse Jaya of being lazy in the house chores and not taking proper care of her baby. Jaya's husband also would shout at her and, at times, become violent.

The situation was aggravated when the husband started to suffer from back pain and had to stop his work as a painter. His mother was paralyzed and nobody else was allowed to work. Electricity was cut and they started cooking with wood and waste found in the vicinity of the slum.

"I was feeling very depressed - Jaya would confide to LSS' Social worker - I was not allowed to go out of the house, and I received no respect at all"

During the follow-up visits, the social worker, herself also a lady, tried to talk with Jaya's husband about the lack of resources that she could have access to. Without much thinking he replied:

“what will she do with the money? We give her food and clothes and fulfil all her needs. It’s her duty to ensure the housework. What would she do outside? Better to be a good wife and to take care of her husband’s family”

But one day, while talking to Meena, the social worker realized that her attitude towards Jaya could change.

"the social worker suggested me to work selling clothes with my sister. Initially I didn't like, but later I turned out to be a great salesman! I started door-to-door sales in rich neighborhood and it's working well."

The social worker helped Jaya to improve her work in the house, often displicent. When Meena noticed these positive changes, she was pleased and even started defending her against her husband’s shouting. Slowly, Jaya started to resist to the violence and oppression that she had been used to. After several months, the husband asked for support to find a job.

For her part, Sofiya has started a handicraft work, making decor items at home and gets income for this. Now she can go out, and became more confident and strong, and is certainly more happy.

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