

DAMIEN SOCIAL DEVELOPMENT INSTITUTE

PROJECT ACTIVITIES REPORT 2017 - 2018

“MISSION LEPROSY (HANSEN’S DISEASE)”

A PROJECT OF DAMIEN SOCIAL DEVELOPMENT INSTITUTE (DSDI)



Submitted By

Damien Social Development Institute (DSDI)

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FEAST OF ST. DAMIEN OF MOLOKAI

PROJECT: MISSION LEPROSY (HANSEN'S DISEASE)

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Introduction:

“Mission Leprosy” or “Mission Hansen’s Disease” has been a project of Damien Social Development Institute (DSDI) of the Congregation of the Sacred Hearts of Jesus and Mary (SS.CC.) in India with its operation base in Bhubaneswar – the capital city of the eastern Indian State of Odisha. DSDI has been serving the persons afflicted by leprosy or Hansen’s disease ever since the Congregation of the Sacred Hearts came to Odisha in 1979. The mission was to carry out the “legacy” of St. Damien of Molokai bringing rays of hope and dignity to the most excluded group of persons in our society – the lepers. The Institute trained doctors and para-medical workers (PMWs) to treat leprosy patients in various leprosy colonies in Odisha. It organized workshops and seminars on leprosy and leprosy patients so as to bring about awareness among the patients themselves and the general public, and to remove existing taboos of social and psychological stigma and exclusion of persons affected by leprosy.

DSDI also carried out housing projects in various leprosy colonies constructing hundreds and thousands of houses providing shelters to patients who had been cast out from their families and from the main- stream of society – (Today as we visit and reconnect with the patients in these colonies and interact with them listening to their stories, they still remember and talk about the person of Fr. William Petrie and express their gratitude). The Institute also carried out various livelihood, vocational training and educational projects in order to rehabilitate the patients, especially those who were cured leprosy patients and their children. Today a significant number of patients in various leprosy colonies have become self-reliant earning their own living with self-respect and self-dignity although a significant number of them also still live on begging.

However, big funding, which used to be available from funding agencies and from governments schemes for the detection of cases, treatment and rehabilitation of patients, have stopped ever since the disease was declared “eradicated” by the UN and by the government of India in 2006. As a result, carrying out of various significant projects, which used to be carried out for the treatment and rehabilitation of patients, has become extremely difficult and impossible. Nonetheless, Damien Social Development Institute (DSDI) continues to be in the service of persons affected by Hansen’s disease and of their children in seven different leprosy slums and colonies in and around Choudwar, Cuttack, Bhubaneswar and Khurda in the eastern Indian state of Odisha. In the year 2017 – 2018, the following service oriented activities were carried out and are being carried out by DSDI for the treatment and rehabilitation of persons affected by Hansen’s disease and for their children.

An On-going Treatment and Rehabilitation of Hansen’s Patients:

Medical and Health: It is an on-going medical treatment of persons affected by Hansen’s disease – especially the treatment of ulcer patients who need daily care of their wounds. Two Damien Clinics have been established with two professional medical doctors and two professionally trained paramedical workers who treat the patients. These doctors and paramedical workers also carry out mobile health camps in seven different leprosy slums and colonies where they conduct treatment and distribution of medicines to patients – for not all patients can travel to the clinics.

Being a religious charitable organization, the objective of our medical and health ministry towards the patients has been: *To treat the patients with human touch and human care.*



(Treatment of patients in Damien Clinic – Choudwar)

Educational and Vocational Training Programs: The target beneficiaries of these particular programs are the children of cured Hansen’s disease patients in the seven leprosy slums and colonies where DSDI has been in service. Statistically, there are about 1047 children of cured patients of whom some hundreds of them are in pursuance of either formal education or non-formal education or of other vocational skills development programs - for, due to certain circumstantial reasons not all children have been put on the path of learning and education which remains an on-going challenge needing more awareness and motivation of parents and children. Those children that are on the path of learning and education, DSDI facilitates their educational pursuance through sponsorship and free tuition/coaching programs both in formal and non-formal education, and in vocational skills development training programs. Much more could be done for the children of cured patients, but due to deficiency in fund availability, DSDI has not been able to initiate and carry out certain creative and innovative projects for the education of children of cured leprosy patients. Your continual support to the Institute would be vital in this regard.



(Formal, Non-formal and Vocational Education of children of cured leprosy patients)

Rehabilitation Projects: In serving the patients affected by Hansen’s disease in seven different leprosy slums and colonies, one of the important challenges DSDI confronts is the rehabilitation of cured patients, especially patients with deformity cases. Although many have been able to establish themselves and earn their living in order to support their families, most patients with deformity cases are not able to help themselves because there is a lack of aids/appliances made

available to them by the Government under Disability Prevention Programs (DPP), such as providing/distribution of artificial limbs, MCR shoes, etc. In the past patients with deformity of legs and limbs were provided with tricycles and crutches, but today they are no longer preferred aids. What are important for the empowerment of patients with deformities are, artificial limbs, MCR shoes etc. However, since over the past several years, with its limited financial resources and funding, what DSDI has been able to do are: establishing weaving center - a livelihood project - for cured women patients who work in the weaving center producing towels, gauges and bandages which are supplied/sold to different hospitals and health centers for income generation.



(Aymer Weaving Center in Gandhipalli Leprosy Colony – Cuttack; Inset: SS.CC. Novices visit)

Another weaving center will be opened and commenced in Shantidan Leprosy colony in Khurda in the month of July 2019 – a colony which had been established by Fr. William F. Petrie, ss.cc., when he was in Odisha from 1979 – 2000. As a livelihood project of DSDI for the cured leprosy women patients, a group of sixteen cured leprosy women from the colony have been identified who will be trained and employed in order to produce gauges, bandages, towels and sarees, and generate income for their families by selling their own products.



(Interaction with the patients of Shantidan Leprosy Colony – Khurda. Inset: Frs. Ajit, Alexis, Radhelal, Bro. Dildhar and Sisters Christina and Jeetima)

DSDI also continues to carry out the projects of reconstruction and renovation of houses of patients – houses which had been built in different colonies several years ago and needing reconstruction, renovation and repair today. Neither the central government nor the state government has any housing scheme for the patients affected by Hansen’s disease. Therefore, the only entity the patients turn to for their shelters is Damien Social Development Institute (DSDI). DSDI has been addressing the issues of reconstruction, renovation and repair of the houses of

patients with the support of Damien – Dutton Society and other generous donors within the Congregation of the Sacred Hearts and its mission collaborators in different Provinces.



(Renovation of houses in Trinath Leprosy Colony in Choudwar)

Awareness Programs: Awareness programs are on-going activities of Damien Social Development Institute (DSDI) which disseminate right information about the Hansen’s disease and about the patients themselves, and their existing situational conditions. They also disseminate information about the patients’ human rights claims before the government and the society, and thus empowering them to assert themselves demanding their fundamental and legitimate rights to exist with human respect and dignity.

Awareness programs are both informative and educational in nature leading towards action plans. They are organized and conducted in the forms of seminars/workshops both in the slums and colonies among the patients themselves and in public forums in networking with other local NGOs and advocacy groups who work for the cause of patients affected by Hansen’s disease and their on-going plights and struggles in the society. DSDI has been an active participant in about seven seminars and workshops and public grievance forums in 2017 – 2018 in order to bring to light the plights, difficulties and struggles of leprosy patients, and present them before the government officials.



(Inset: Fr. Alexis Nayak, ss.c. addressing the gathering at a workshop on rehabilitation)

Awareness programs in seminars and workshops are focused mainly on the following dissemination of information:

- Right information about the Hansen’s disease and the reasons for its spread. The objective is to prevent misconception about the disease in the grass-root level because the taboos, misconception and the reality of exclusion still exist among the general public.
- Right information about the early detection of cases and following up with MDT medication rehabilitation for complete cure. The objective is to prevent instances of deformities. For physical deformities make the patients victims doubly.

- Right information about maintenance of health, hygiene, sanitation, rational use of medicines and rehabilitative self-care practices in order to prevent disabilities.
- Awareness on prevention of discriminatory social stigma and exclusion of patients, and promotion of social inclusion and integration in the main-stream of society.
- Awareness on the acceptance of patients and avoidance of untouchability. The objective is to promote both psychological and social inclusion instead of exclusion which still exists.
- Awareness on patients' fundamental and legitimate rights to health, food, shelter, education and other governmental social welfare schemes, such as: housing, basic civic amenities, adequate sanitary facilities and rehabilitation programs. The objective is to empower them to assert themselves claiming what rightly belongs to them for their existence as human persons.
- Awareness on the right of patients' non-discriminatory accessibility to both public and private hospitals for medical and health treatments, and their children's non-discriminatory accessibility to both public and private schools for free education as guaranteed in 2016 by the Supreme Court of India.



(Networking with other NGOs for the Public Hearing of Grievances of Leprosy affected and cured patients in Odisha)

Actions Plan for an Integral Rehabilitation: Our proactive engagement and interaction with the patients all these years have made us realize that it is not just enough organizing awareness programs in order to disseminate information among patients and their children in different leprosy slums and colonies. Nor is it enough doing situational analysis of patients and their children in leprosy slums and colonies. What is important is: devising actions plan and implementing them for an **integral rehabilitation**; for, an integral rehabilitation of cured patients of Hansen's disease and their children is the need of the hour. This is the cry of the patients in leprosy colonies whenever we are in interaction with them. Therefore, Damien Social Development Institute (DSDI) is actively striving towards such an integral rehabilitation of cured leprosy patients and their children. From its situational analysis of patients and their children in slums and colonies and from the public grievance hearing of patients in different public forums, DSDI has been able to identify the following needs and challenges of cured patients and of their children which need to be paid attention to:

- Constant accompaniment and empowerment of patients and of their children.
- Prevention of begging and rehabilitation of cured patients through livelihood and income generation programs.
- Prevention of further disabilities of patients by availing artificial limbs and MCR shoes. Therefore, need for a disability prevention medical rehabilitation clinic (DPMRC) for patients.

- Continual sponsorship programs for the children of cured patients for their formal higher education and vocational skill development training and capacity building.
- Advocacy for the appointment of professionally trained paramedical workers for the detection of patients and disease, urgent treatment of patients and prevention of disabilities. There are 404 paramedical workers post in government hospitals under National Leprosy Eradication Program (NLEP). However, 350 posts remain vacant without any appointment of paramedics. DSDI has professionally trained about 30 paramedical workers from different leprosy slums and colonies but none of them have been appointed by the government.
- On-going accompanying and empowering the patients to assert themselves before the government and to demand from it the certificates of ownership of their houses in slums and colonies. For, although the patients have been allotted land for the construction of houses under the rehabilitation program which Fr. William Petrie did many years ago, the Government has not given the patients the *pattas* - the certificate of ownership of their houses in slums and colonies. Hence the land mafias, in connection with politicians, encroach/grab their land and threaten them of eviction.



(Community and capacity building animation workshop in Leprosy Colonies)

Threat to Mission Leprosy (Hansen's disease):

India is going to celebrate the 150th birth anniversary of Mahatma Gandhi on 2nd October 2019. In the event of this celebration, the Union Health Minister Dr. Jagadish Prasad Nadda has decided and has already made an announcement that India would be declared “Leprosy Free” on the 2nd October 2019. The decision of the Union Government has been causing lots of fears and anxieties among the leprosy patients and those working for the cause of leprosy and the patients. The decision is totally against the data that are available in public domain. It is an undeniable fact that since India was declared “Leprosy Eradicated” in 2006, there has been a steady and gradual increase in the detection of new leprosy cases in India. According to the survey data of 2017 – 2018, there were a total of 95359 new leprosy cases detected and in the state of Odisha alone there were 5700 new leprosy cases detected as of January 2019 survey data. The intention of the Government is very clear: keep hiding the data and the reality of the disease, and project itself before the world with a good image. If the decision is carried out as declared by the Union Health Minister, the resultant consequences could be the following:

- There will not be any allocation of budgets for the cause of leprosy and leprosy patients both in the Central Government and in the State Government annual budgets. As a result, any research work on leprosy, production and supply of MDT, detection of new leprosy cases and their treatment, appointment of professional and trained personnel for leprosy detection and treatment will be totally affected.

- There will not be any more Government schemes for the rehabilitation of leprosy patients and their children: schemes such as, prevention of deformities, livelihood projects, free-medical treatment both in public and private hospitals, and free-educational programs for the children of cured leprosy patients both in the Government and Private schools which are totally against the verdict of the Supreme Court of India in 2016.
- As a result of the above, the grave consequence will be the increase in the number of new leprosy cases which will go undetected and un-treated, and the increase of the plights of leprosy patients spread across India and in the State of Odisha in particular. This will certainly cause a serious and catastrophic public health issue in India.

Damien Social Development Institute (DSDI) has been partnering with other NGOs and with other independent individual activists who work for the cause of leprosy and leprosy patients in mobilizing the leprosy patients in various leprosy slums and colonies in order to submit a memorandum to the Government of India with a demand to halt the proposed declaration on the 2nd of October 2019 “Leprosy Free India”. There have been seminars, workshops and press conference in order to bring about awareness among the leprosy patients and among the general public as well.

Conclusion:

On behalf of the Congregation of the Sacred Hearts (SS.CC.) in India and on behalf of the leprosy patients, who are the main stakeholders and beneficiaries of the project, Damien Social Development Institute (DSDI) of the Congregation of the Sacred Hearts of Jesus and Mary (SS.CC.) in India would like to thank Damien – Dutton Society for its Grant towards the leprosy treatment and rehabilitation and to all our individual donors or a group of donors in different Provinces of the Congregation of the Sacred Hearts world-wide.

We remain grateful to you for your support and collaboration with the project “Mission Leprosy” of DSDI. You are making a difference in the lives of people affected by the Hansen’s disease (Leprosy) and giving them a “ray of hope” for their existence. ***Please do continue to support our mission with them and for them for the project year 2019 - 2020.*** India is far from the slogans of “Leprosy Eradicated” or “Leprosy Free”. Research has indicated that it is making a gradual come back in India and if it is further neglected with constant denial, it can create a catastrophic public health issue in India.



(Fr. Alexis with the patients)

The photos inserted speak for themselves about the reality. In one family, three members have been detected with leprosy (positive) and are being treated in a rehabilitation center. The

photos have been taken in March 2019 when I visited them in the center where DSDI has also been working in collaboration. Once again, Thank You and God bless you!

End Note:

This Activities Report is specifically of the project “Mission Leprosy 2017 - 2018” of Damien Social Development Institute (DSDI). Financial statement of the utilization of Grants and donations received during the year 2017 – 2018 has been attached herewith. A separate global Annual Report of DSDI projects and ministries will soon be brought out in the end of May 2019.

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