Project for the

Prevention of Impairment and Disability (POID)

in

Guntur & East Godavari districts of Andhra Pradesh

END EVALUATION REPORT

(March 2014)

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Prepared & Submitted by

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Implemented by

Greater Tenali Leprosy & Education Scheme Society (GRETNALTES)

&

Rural India Self Development Trust (RISDT)

Supported by

FAIR MED

Health for the poorest

ACKNOWLEDGEMENTS

We wish to thank Mr. John Kurien George and Dr. Akshaya Kumar Mishra of Swiss Emmaus Leprosy Relief Work India for their helpful guidance in the entire process of this evaluation and for their valuable inputs in the draft report. We are indebted to the Mr. Hemachandu of GRETNALTES, Guntur district and Mr. Slesser Babu of RISDT, East Godavari district for the excellent and traditional hospitality extended during our stay in the districts and for sharing practical views and experiences in implementing this project. We acknowledge the immense contribution of Mr. Shiva of GRETNALTES and Mr. Prasad of RISDT for planning and organizing the field visits meticulously and for providing technical information on the project as well as the photographs used in this report. We thankfully acknowledge the services rendered by the entire project teams of NGO partners for their active participation and support in facilitating the entire evaluation process smoothly and efficiently in both the districts.

We thank all the health staff of NLEP units and PHCs / CHCs including ASHA and ANMs in Guntur and East Godavari districts for their wholehearted support and cooperation during the evaluation. We thank the state and district NLEP officials as well as DRDA authorities for their useful interaction on this project. We would further like to acknowledge the positive inputs given by all the people affected by leprosy who attended the POID camps during this evaluation in these districts. All the logistics and expediency services provided by the Project team and administrative staff of both NGO partners is highly appreciated. We wish to thank Mr. A. Antony Samy, Chief Executive, ALERT-INDIA, Mumbai for the valuable guidance and cooperation. Finally, we would like to express our sincere gratitude to FairMed for giving this opportunity.

Evaluation team with Project team of Greater Tenali Leprosy & Education Scheme Society (GRETNALTES) of Guntur district

Evaluation team with Project team of Rural India Self Development Trust (RISDT) & PHC staff in East Godavari district

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i. ABBREVATIONS

AAY	:	Antyodaya Anna Yojana
ANCDR	:	Annual New Case Detection Rate
ANM	:	Auxiliary Nurse and Midwife
AP	:	Andhra Pradesh
APMO	:	Assistant Para Medical Officer
APVVP	:	Andhra Pradesh Vaidhya Vidhana Parishad
ASHA	:	Accredited Social Health Activists
ATP	:	Advance Tour Programme
CBI	:	Community Based Initiatives
CBR	:	Community Based Rehabilitation
CHC	:	Community Health Care
CLD	:	Central Leprosy Division
DHAP	:	District Health Action Plan
DISPEL	:	Disability Prevention and Education in Leprosy
DLO	:	District Leprosy Officer
DLS	:	District Leprosy Society
DM&HO	:	District Medical & Health Officer
DNT	:	District Nucleus Team
DPMO	:	Deputy Para Medical Officer
DPMR	:	Disability Prevention & Medical Rehabilitation
DRC	:	District Rehabilitation Centre
FGD	:	Focus Group Discussion
GHC	:	General Health Care
GoI	:	Government of India
GO-POID	:	Government Officer - Prevention of Impairment & Disability
GRETNALTES	:	Greater Tenali Leprosy and Education Scheme Society
HEO	:	Health Education Officer
IEC	:	Information, Education & Communication
IKP	:	Indira Kranthi Pathakam
ILEP	:	International Federation of Anti-leprosy Associations
LPT	:	Leprosy Physiotherapy Technician
MCR	:	Micro-Cellular Rubber
MDT	:	Multi-drug Therapy

MO	:	Medical Officer
MPHS	:	Multipurpose Health Supervisors
NFA	:	Nerve Function Assessment
NFI	:	Nerve Function Impairment
NGO	:	Non-Governmental Organization
NLEP	:	National Leprosy Eradication Programme
NRHM	:	National Rural Health Mission
NSAP	:	National Social Assistance Programme
PAL	:	Persons Affected by Leprosy
PCM	:	Project Cycle Management
PHC	:	Primary Health Care
PIP	:	Programme Implementation Plan
POID	:	Prevention of Impairment and Disability
PPT	:	PowerPoint Presentation
QoL	:	Quality of Life
RCS	:	Reconstructive Surgery
RISDT	:	Rural India Self Development Trust
RKS	:	Rogi Kalyan Samithi
SADAREM	:	Software for Assessment of Disabled for Access Rehabilitation & Empowerment
SCG	:	Self Care Groups
SERP	:	Society for Eradication of Rural Poverty
SERP	:	Socio-Economic Rehabilitation
SHC	:	Self Help Groups
SLO	:	State Leprosy Officer
SPHO	:	Senior Public Health Officer
SSAU	:	Sample Survey Assessment Unit
THW	:	Temporary Hospitalization Ward
ToR	:	Terms of Reference
ToT	:	Training of Trainers
UHC	:	Urban Health Centre
VHSC	:	Village Health & Sanitation Committee
WHO	:	World Health Organization

ii. EXECUTIVE SUMMARY

The pilot project **"Prevention of Impairment and Disability (POID)"** implemented by NGO partners in Guntur (GRETNALTES) & East Godavari (RISDT) districts of Andhra Pradesh from 2010 to 2013 primarily aimed at maximizing the capacity of health personnel of NLEP & PHCs to meet the physical and social needs of people affected by leprosy through camp approach. The project team has coordinated well with the NLEP and GHC staff for implementing the POID activities in the districts.

This project had responded rapidly to the needs and priorities of the persons affected by leprosy by incorporating the POID activities into the NLEP in the districts and have considerably reduced the inequality and the 'social distance' between health service providers of the GHC system with the persons affected by leprosy.

iii. KEY CONCLUSIONS AND RECOMMENDATIONS

This POID project has effectively demonstrated the establishment of leprosy service network in the districts within the framework of GHC system that include provision of POID services through camps thereby making the services more affordable and accessible to persons affected by leprosy. Providing opportunities to the GHC staff for assuming complete ownership of the POID activities under NLEP is one of the positive effects of this project. While, the NGO partners has played the role of a complimentary service provider, this project has been generally perceived as an 'NGO initiative' and not regarded as a crucial initiative under NLEP by the government health functionaries and officials at all levels.

Implementation of self-care practice during the POID camps as an effective means of preventing secondary damage as perceived by the persons affected by leprosy with disabilities in limbs and eyes is encouraging. Provision of 13,711 MCR footwear and 18,871 dressing kits to persons affected by leprosy in the districts is impressive and that has increased the compliance and turnout to POID camps.

Sensitization of health care providers at PHCs and CHCs in responding to the needs of persons affected by leprosy through training and retraining and involvement of ASHAs for provision of self care and awareness generation have enhanced their effective participation in POID activities to a limited extent. There is a need to review the training contents for various categories of health personnel with participatory methods to provide more technical and practical experiences on the POID strategy as recommended by NLEP.

Mainstreaming the rehabilitation services for the persons affected by leprosy and the people with disabilities other than leprosy through self help groups is a best practice; however this aspect needs to be strengthened. A significant achievement of this project has been to coordinate with the social welfare departments of state government in the districts to issue 'disability' certificate to 2,355 persons affected by leprosy in order to avail concessions and economic support from the Government. The coordination mechanisms adopted by the NGO partners have been useful to fulfill the socio-economic requirements of 2,759 persons affected by leprosy in the districts.

The reporting systems and information sharing about the achievement of this project was comparatively weak, which is to be streamlined with standard procedures and protocols. The NGO partners should focus on developing a uniform guideline for data collection and mechanisms for technical monitoring of the POID project.

The technical support and inputs provided by backstopping exercise under this project were sufficiently justified in increasing the capacity of the health personnel and enhanced the quality management of leprosy in the districts. Besides, this POID project has also strengthened the referral system and linkages with the tertiary care centres of the NGO partners for provision of comprehensive leprosy services including 667 persons affected by leprosy with cataract surgery and 427 persons affected by leprosy with reconstructive surgery for correction of their disabilities and deformities.

The NGO partners should build on the strong position it has acquired through this project and remain actively involved in leprosy control work in the district for few more years with new plans and priorities for transferring the ownership of the activities to the public health system in these districts. Although, this POID project has accomplished the short term results and its objective, there is a need to put stronger processes in place to strengthen the NGO partners with highly engaged and professional staff for monitoring the project.

It is further stressed that the FairMed has a mandate and working collaboration with the NLEP units in the state that could be utilized to engage the Government with specific work plans and enable joint monitoring of the project activities in the districts. FairMed can showcase the modalities of this POID project that is likely to be a reflection of aligned priorities of the NLEP in the state and national level. FairMed can also influence the Government to strengthen the policy and actions with adequate systems that can sustain the POID activities with more vitality and dynamism.

1. INTRODUCTION

Disabilities and deformities are the consequence of nerve damage in people affected by leprosy leading to stigma and discrimination. It is possible to prevent nerve damage by detecting of people affected by the disease at an early stage and treat adequately with multi-drug therapy (MDT). Nevertheless, due to delayed case finding in the integrated health system, around 5% to 8% of new leprosy cases detected in the country have permanent nerve function impairment (NFI). A prospective cohort study on the occurrence of new nerve function impairment in new leprosy cases during and after MDT have shown that the risk of developing new NFI was 6% for PB cases and 18% for MB cases who were initially free from NFI at the time of diagnosis[1].

In the present structure of integration, early detection and treatment of NFI due to leprosy is still not the main concern of the general health care (GHC) system. This strongly emphasizes the need for preventing new disabilities and deformities among the leprosy cases under MDT. Therefore the interventions that prevent, reverse or limit the NFI resulting from leprosy are of the highest priority. It has been estimated that in 2015, there will be nearly 500,000 people living in India with grade 2 disability due to leprosy, who need specialized care even after cure[2]. To achieve this, identification and treatment of early NFI is obviously necessary, but it must be accompanied by a comprehensive care for the persons affected by leprosy and assist in complete rehabilitation.

In 2001, FairMed have launched a project on **'Disability Prevention and Education in Leprosy' (DISPEL)** in 6 districts of Andhra Pradesh that delivered prevention of disability (POD) services by a special team to several persons with disabilities and deformities due to leprosy through general health service network. An internal review of this project, while distinguishing its success, further recommended that the project need to focus on prevention of impairment and disability (POID) and adopt a more holistic and a sustainable approach.

In consideration of the lessons learnt through DISPEL project, FairMed has proposed a pilot project **"Prevention of Impairment and Disability (POID)"** in 2010 that was implemented by 2 NGO partners (GRETNALTES & RISDT) in 2 districts (Guntur & East Godavari districts) of Andhra Pradesh from 2010 to 2013. These NGOs are key partners supported by FairMed that run leprosy hospital and provide tertiary care leprosy services in the districts. This pilot POID project deliberately made a comprehensive effort for preventing NFI and its consequences in persons affected by leprosy, new and cured within the framework of primary health care system through a camp approach. This project also strengthened partnership with GHC system and made collaborative working arrangements with National Leprosy Eradication Programme (NLEP) and other social establishments of the government in these districts to provide POID services to people affected by leprosy in an integrated manner.

2. CONTEXT OF THE EVALUATION

2.1 FairMed's health policy - 'health for the poor'

Swiss Emmaus Leprosy Relief Work India (SEI), established since 1957 and supported by FairMed (Switzerland) - **herein referred to as "FairMed" –** is working with a vision of **'Health for the poorest'**, where no one in this world suffers any longer from leprosy and other poverty-related diseases or experiences discrimination because of disease or physical disability and deformity. FairMed aims to find a '**customized solutions to Indian problems**' by targeting health problems of the poorest of the poor and marginalized people and assist NGO Partners to work along with Government in order to ensure 'right to health for the poor' thereby bring about sustainable development. FairMed is committed to improve the lives of people affected by leprosy, tuberculosis and other poverty related diseases through social and medical rehabilitation. FairMed is one of the 9 members of International Federation of Anti-Leprosy Organizations (**ILEP**) actively working to fulfill the objectives of NLEP. FairMed is currently supporting and managing 10 projects focussing on public health and integrated rehabilitation with reference to leprosy in eight states of India.

2.2 FairMed's strategy for leprosy - 'improving quality of life of persons affected by leprosy'

FairMed has implemented a 3 year pilot project **"Prevention of Impairment and Disability (POID)"** through 2 local Non-Government organizations (NGO) – **herein referred to as "NGO Partners"** – Rural India Self Development Trust (RISDT) in East Godavari district and Greater Tenali Leprosy & Education Scheme Society (GRETNALTES) in Guntur district in collaboration with Govt. of Andhra Pradesh. The project activities covered all the public health facilities such as Primary Health Centres (PHCs), Community Health Centres (CHCs) and Urban Health Centres (UHCs) including leprosy colonies in both these districts since September 2010. This project principally aimed to improve the quality of life of persons affected by leprosy by ensuring prevention of disability and rehabilitation services involving NLEP and the GHC system at the primary level.

In this context, FairMed planned this pilot project to put together a revamped strategy aimed at maximizing the capacity of health personnel of NLEP & PHCs to meet the physical and social needs of people affected by leprosy through camp approach. **POID activities** were more functionally integrated with the basic leprosy services provided at the primary level of GHC system through the initiatives of this project successfully. This new strategy was presented at the International Leprosy Congress held in Brussels during September 2013 and has acclaimed universal recognition by bagging award as 'best presentation'. FairMed would draw lessons, document best practices and experiences and also understand the processes through the end evaluation of this project so as to replicate this model in other states / districts of the country.

2.3 The Project for the Prevention of Impairment and Disability (POID) in Andhra Pradesh

In order to implement the project measures (activities) as described in the proposal, the NGO partners have administered the following actions for providing POID services to persons affected by leprosy within the framework of primary health care system and linked to FairMed supported NGO hospital based centres for specialized services in the districts.

- **Organization of POID camps**

The project team of the NGO Partners prepares Advance Tour Programme (ATP) for the POID camps to be conducted at identified PHCs and submits the plan to Additional District Medical & Health Officer (AIDS & Leprosy) – designated as District Leprosy Officer – of respective districts with a copy to the concerned Medical Officer (MO) of the PHCs. The District Leprosy Officer (DLO) of the districts informs the concerned APMO & DPMO responsible for the PHC about the camp dates. The MO of the PHCs informs the designated Government officer – Prevention of Impairment and Disability (GO-POID), along with the PHC staff and ASHA, mobilize the leprosy cases for the POID camps.

- **Mobile teams for conducting POID camps**

The POID camps are mainly conducted by a mobile team consists of 1 Leprosy Physiotherapy Technician (LPT), 1 Counsellor and 1 dresser and assisted by APMO and DPMO. Persons affected by leprosy including those with disabilities and deformities were encouraged to attend the POID camps on their own to avail the POID services that provided at PHC during the camp. The mobile van is also used to transport immobile persons due to leprosy, old age and other medical conditions from the nearby villages for the POID camp. These POID camps were repeated one in 3 months in every PHCs and CHCs, including the UHCs of these districts. Mobile teams also visit the leprosy colonies in the districts and extend POID services to the inmates.

- **Assessment of nerve functions in leprosy cases**

All leprosy cases including those cured of leprosy (old cases) who attend the camps were assessed (Nerve Functions) using the SWIFT Form (Used under DISPEL project) once in 3 months by the mobile team of the NGO Partners. The respective APMO or DPMO also does NFA of the new leprosy cases under MDT (active cases) and record the findings in NLEP P-II Form.

- **POID services rendered during the camp**

The POID services such as soaking, massage and oiling as well as wound dressing were provided by the mobile team. MCR footwear (Leprosy cases with Grade 1 disability in feet) and dressing kits (dressing materials for 1 week) were provided to needy leprosy cases during the POID camp. Appropriate leprosy cases were referred to NGO centres for specialized treatment.

- **Joint actions and coordination**

In order to promote synergies, the Project has undertaken joint actions and made a breakthrough in ***mainstreaming the rehabilitation services*** for the persons affected by leprosy and the people with disabilities other than leprosy through an integrated approach. Coordination with other ***community based welfare programmes*** of the Government is a key part of the project, which has a social dimension within their respective health related activities that has averted the inequalities. The project also attempted to promote ***community actions*** through self help groups that are likely to have an impact on the socio-economic development.

3. EVALUATION FRAMEWORK AND APPROACH

3.1 Rationale and scope of evaluation

The evaluation covered as far as possible evidencing the implementation experience of POID camps by the project teams in the Guntur and East Godavari districts of Andhra Pradesh in relation to the short term results as per the project measures. The evaluation team comprehends this to be a formative evaluation, which will assess the **implementation and achievements** of the POID project by an analysis of the 'outputs' gained through the efforts of the NGO partners and their contribution to each of the objectives of the Strategy. Through a participatory approach, the evaluation assessed the perception of the direct beneficiaries – Persons affected by leprosy – on the effectiveness of the services provided at the POID camps. This allowed the evaluation team to identify the process as well as the lessons learned from the Strategy's implementation in Guntur and East Godavari districts of Andhra Pradesh.

The team also ventured into recording the best practices of this POID project in health promotion and in addressing the 'disability burden' and issues from the public health perspective. As the priorities and actions of the POID project has relevance to the principles of 'community based rehabilitation', a concept recommended by WHO for promoting community participation, the evaluation explored the context and appropriateness of this POID project in demonstrating and impersonating a CBR model.

3.2 Objectives and time frame

The objectives of this evaluation are to assess the implementation and effectiveness of the POID project for the period of 3 years (2010-2013) including the coordination mechanisms and to carry out a process assessment to see whether the principles and objectives based on the evaluation points as mentioned in the Terms of Reference (ToR) were achieved ***(Refer Annexure 1)***, as well as to prioritize the activities and suggest directions for the future prospects or scaling up of this project in additional districts within Andhra Pradesh state as well as inter states within India.

As stipulated in the task specifications agreed in ToR proposed by FairMed, the end evaluation was planned and accomplished as per the following time frame.

Sl. No.	Task specifications	No. of Days	Time line
1	Desk Review, Developing and finalization of Tools (questionnaire, FGD guides, Interview guides etc).	5 days	26.11.2013 to 30.11.2013
2	Consultations with state level officials; Project site observations visit in the districts; In-depth interviews (10% of total) with all stakeholders; FGD with beneficiaries; meeting and discussions with project staff & district level officials.	14 days	08.12.2013 to 21.12.2013
3	Analysis and transcription of data (both qualitative and quantitative).	3 days	26.12.2013 to 05.01.2014
4	**Reporting:** Draft report & Final report submission after including suggestions, corrections based on review of Swiss Emmaus team.	7days	
5	Dissemination of end evaluation findings - PPT (To be decided by FairMed)	1 day	
	Total Number of days	**30 days**	

3.3 The approach for End Evaluation

The scope and design of the evaluation is to assess the process of implementation and the outcomes of POID services delivered in collaboration with the GHC system and also guide the FairMed going forward and take stock of the actions implemented in both the districts in order to develop future strategy. Evaluation methodology is based on the mix of participatory consultations with the stakeholders through personal interview, together with practical field observation the process of the implementation and responses of key actors involved in the project provided a useful basis for identifying some key trends and developments that were the direct results of the POID project. Moreover, the evaluation will seek to assess the effectiveness of the POID strategy, notably whether it has generated any policy impact at state and country level, and whether it has contributed in adding value to the leprosy control work of NLEP and/or influenced other stakeholders and public health authorities in the GHC system. In addition it is envisages that the results of activities will be carefully judged, both positive and negative impact and potentially used when formulating future strategy of this POID project.

4. EVALUATION METHODOLOGY AND TOOLS

4.1 Stakeholder's interview

A set of questionnaire tools were developed to gather first-hand information on the outputs and impacts of the POID project at all levels of GHC systems including the persons affected by leprosy as a 'right holder'. The tools allowed to gather information on the relevance of the key actions planned at district level that were undertaken as a direct (or indirect) result of the project (i.e. outputs); and the extent to which the POID project has impacted on GHC systems (i.e. impacts) in delivering POID services to the persons affected by leprosy. Personal interviews with all the stakeholders of the government as well as the NGO Partners involved with POID project in the targeted districts – Guntur & East Godavari were conducted through field visits to gather their views and perceptions. Details of the respondents are given in Annexure 2.

4.2 Desk review tasks

As a part of desk review, the evaluation team collected relevant project documents, review / mid-term assessment and back stopper reports and official Programme Implementation Plans (PIP) of the NLEP and its performance in the targeted districts as well as in the state of Andhra Pradesh. The important information were summarized from these documents and used for mapping the outputs at all level in relation to the POID project during the evaluation process.

4.3 Sample selection

- **Selection of areas for field visit**

The review of 10% sample of GHC facilities - 14 PHCs, 1 CHC, 2 THWs, 2 ULCs, 1 SHG & 1 leprosy colony - were selected for field visits with due deliberation of optimal geographical coverage in Guntur and East Godavari districts. No set criteria were used to select the GHC centres except the PHCs that are predefined for POID camp as per the ATP during the evaluation period. For a comparison, the adjoining West Godavari district was selected as a control area where the routine leprosy control activities were carried out by the NLEP staff in collaboration with the PHC staff.

- **Selection of respondents for in-depth interview**

The FairMed in coordination with their NGO partners organized the meetings with the state and district level health and social sector officials in both the districts. The key respondents – NLEP and PHC staff including GoPOID – who were involved in POID project and those available at the GHC facilities, were interviewed during the field visit. The focused group discussion was targeted with ASHAs and ANMs as well as the persons affected by leprosy who were present at the respective GHC facilities. Despite efforts, NRHM officials in the state and district could not be interviewed.

5. VIEWS AND PERCEPTIONS OF KEY STAKEHOLDERS

5.1 Programme level health officials at the state and districts

i) Dr. Tarachand Naidu, State Leprosy Officer, Govt. of Andhra Pradesh, Hyderabad, Andhra Pradesh

- **Level of leprosy integration into the general health care system:**

It is premature and that the leprosy is not a priority of the PHCs. The entire NLEP activities are still on the shoulders of the specially trained leprosy personnel (vertical NLEP staff) and there is an acute shortage of trained leprosy personnel in the state as 30% of APMOs are due for retirement in the next few years.

- **Increasing trend of disability due to leprosy during the last 3 years:**

It is reported that 412 (4.9%) out of 8295 new leprosy cases detected during 2012-13 had visible disabilities (Grade 2) at the time of diagnosis, which is slightly higher than the previous 3 years. The Information, Education and Communication (IEC) activities carried out at present by the NLEP staff are not effective in early detection of new leprosy cases and the use of audio-visual media such as TV need to be explored for creating General awareness about leprosy.

- **Increased new case detection during 2012-13 in AP state:**

There is no intensified new case detection activities carried out by the PHC staff routinely except during the special search activities in the identified high endemic (ANCDR >10 / 100,000 population) blocks of the state. Till March 2012, 58,535 ASHAs were trained in leprosy by NLEP and about 30% to 40% of new leprosy cases registered in the State is diagnosed among the suspects referred by ASHA. The state government has recently launched new software for online reporting system of tasks carried out by ASHAs; hence no delay in payment of cash incentives to ASHAs for diagnosis and treatment of new leprosy cases among the suspects referred under NLEP. Over utilization of the cash incentives to ASHAs is a matter of concern and no mechanism for confirmation of cash transactions at PHC level.

- **Training and capacity building of health personnel at PHC:**

Majority of the medical and health personnel at the PHCs including ASHAs are trained in leprosy by the district level NLEP units. Planning to train all newly appointed medical officers and health workers of PHC including the Pharmacists and Laboratory Technicians in leprosy through the 'training cell' specially constituted at the state health directorate in Hyderabad. Refresher training in leprosy for the medical officers of PHCs is also planned during 2013-14. Few contractual posts for the identified high endemic districts as proposed in the NLEP PIP is yet to be recruited, trained and inducted. Training of medical and health personnel serving at the Area and district hospitals in leprosy orientation are not considered as they are under the Andhra Pradesh Vaidhya Vidhana Parishad (APVVP), which is not responsible for implementing national public health programmes in the AP state.

- **NLEP activities in the AP state:**

Unenthusiastic about the contribution by trained leprosy personnel (DPMO & APMO) of the Government towards DPMR services to the extent possible in the districts. Currently, the leprosy trained personnel of NLEP conducts POD camps in 96 self settled leprosy colonies across the state and also provide dressing materials once in 15 days. The provision of funds by the Central Leprosy Division (CLD) of Govt. of India (GoI) for the supply of micro cellular rubber (MCR) footwear is very limited and are restricted only to people affected by leprosy living in leprosy colonies. There are 9 identified RCS centres in the state and 8 are managed by NGOs and 1 by the Government. No surgery is done in the identified RCS centre of the Government as the surgeons are reluctant to operate people affected by leprosy due to stigma and lack of skilled training. The Govt. of AP is supporting 29 Temporary Hospitalization Wards (THW) each with 20 beds (10 for leprosy + 10 for HIV AIDS) in all 23 districts managed by 1 Medical Officer, 3 Staff nurse and 1 laboratory technician. Besides, the Govt. of AP is also running 2 regional level (Hyderabad & Guntur) Sample Survey Assessment Units (SSAU) with mobility support for validating the disease burden through sample survey conducted periodically in the selected blocks of the districts. These two initiatives are unique activities under NLEP in the AP state.

- **Future goals of NLEP in AP state:**

Reducing the number of new leprosy cases detected with grade 2 disabilities is the priority issue of the Government and the best strategy to achieve is to detect them at an early stage. Encourage the NGOs to implement District Referral Centres (DRCs) under the NGO scheme supported by Central Leprosy Division in all the districts.

- **POID AP Project:**

The strategy adopted under the POID project is ***in line with the NLEP priorities*** and it has been a success in terms of ***strengthening the integration into the GHC system*** in the districts. The POID camps organized by the NGO Partners in Guntur and East Godavari districts are useful in reinforcement of NLEP activities but not sure whether these camps can be sustained by the AP State. These camps also sensitized the PHC staff to a greater extent in providing comprehensive leprosy services. Recommends conducting such POID camps in Vijayanagaram and Ananthapur districts that are known to be endemic for leprosy. Acknowledged the provision of aids such as MCR footwear and Dressing materials (Kits) by the NGO Partners to the needy leprosy cases in these districts with their own funds. Reconstructive surgery (RCS) services provided by these NGO Partners are commendable as it helps to achieve the annual target set under NLEP for the State. No reimbursement for RCS services is given to these NGO Partners from the Government as per the agreement made with Govt. of India and ILEP agencies towards contribution to NLEP. NGO Partner (GRETNALTES) is receiving SET grants under NLEP from the Government of AP every year for basic leprosy control work in Guntur district.

ii) Dr (Mrs). P. Umadevi, Additional District Medical & Health Officer (AIDS & Leprosy), Guntur district

The Programme Implementation Plan (PIP) for the NLEP activities in the district under NRHM is prepared by the State Leprosy Office in consultation with the Health, Medical & Family Welfare Department, Govt. of Andhra Pradesh, Hyderabad. Not involved in preparing District Health Action Plan (DHAP) under NRHM, hence not aware of the provisions of funds for various activities to be carried out under NLEP in the district. Funds for NLEP activities are released by the State Leprosy Office to the District Leprosy Society (DLS) with specific instructions on the utilization. Post of Medical Officer in District Nucleus Team (DNT) is vacant since a few months. The existing members of the DNT were trained by LEPRA India, coordinating ILEP agency for the Andhra Pradesh State. All the Medical Officers and staff of 84 PHCs in the district were trained in leprosy by NLEP and FairMed team. POID camps conducted by the NGO partners have enabled several persons affected by leprosy to receive MCR and dressing kits. This POID project as well as the DISPEL project has facilitated to collect information on the persons affected by leprosy with disabilities in the district and such activity need to be continued for at least few more years to strengthen the NLEP.

iii) Dr. Pawan Kumar, Additional District Medical & Health Officer (AIDS & Leprosy), East Godavari district.

The Programme Implementation Plan (PIP) for the NLEP activities in the district under NRHM is prepared by the State Leprosy Office in consultation with the Health, Medical & Family Welfare Department, Govt. of Andhra Pradesh, Hyderabad. Not involved in preparing District Health Action Plan (DHAP) under NRHM, hence not aware of the provisions of funds for various activities to be carried out under NLEP in the district. Funds for NLEP activities are released by the State Leprosy Office to the District Leprosy Society with specific instructions on the utilization. Orientation including refresher training in leprosy was conducted to all Medical Officers of PHCs for one day and the PHC staff for 2 days by NLEP and FairMed team. Involvement of PHCs in leprosy control activities was not on the expected lines and the presence of the NLEP staff is a deterrent factor for integration of leprosy into GHC system who did not assumed the full ownership of NLEP in the state.

Unable to provide sufficient dressing kits and MCR footwear to the persons affected by leprosy confined permanently in 17 self settled leprosy colonies in the district due to lack of funds and non clarity on the budget line items under NLEP. There is definite shortage of supply of dressing kit and materials at PHC also. There was confusion with regard to payment of incentives to ASHA under NLEP as sometime back at few centres ASHAs were getting incentives both from NRHM and NLEP. It is suggested that the incentives to ASHAs from NLEP should be transitioned to NRHM so that there is proper ownership, better accountability and easy disbursal without duplication.

iv) **Dr. Y. Kameshwar Prasad,** Medical Officer, Sample Survey Assessment Unit, Guntur district.

Recent sample survey conducted in 3 PHCs having 'ZERO' leprosy prevalence revealed 8 new leprosy cases among 1,975 population screened, giving a New Case Detection Rate (NCDR) of 405 per 100,000 population. The proportion of child cases among the new leprosy cases detected through sample survey is alarming, which confirms active transmission of leprosy infection. Therefore, ascertained that the actual disease burden due to leprosy (New leprosy case detection) would be considerably more than what is currently being reported by the Government. Non availability of skin smear facility in the General health system makes it difficult to diagnose persons with lepromatous (infectious type) leprosy, thereby aid transmission of leprosy infection in the community, hence the new leprosy cases will continue to occur. Low prevalence and incidence of leprosy as reported in several districts of Andhra Pradesh were attributed to poor performance of PHC staff in new case detection and non-availability of trained leprosy staff (DPMO / APMO) in the districts. Need to strengthen new case detection activities in order to sustain the gains made so far.

v) **Mr. G. S. Sunder Raj,** Project Officer (CBR), Indira Kranthi Pathakam - DRDA, Guntur district

Under the Society for Eradication of Rural Poverty (SERP) / Indira Kranthi Pathakam (IKP) schemes, any person affected by leprosy with more than 40% disability will be certified and given Rs.500 per month as pension. More than 1,600 persons affected by leprosy have been assessed through the special SADAREM camps and are being given pensions in Guntur district in coordination with GRETNALTES, a NGO Partner in Guntur district. The processes for conversion of disabled persons including persons affected by leprosy for getting pensions from other schemes to the existing scheme is being consolidated and this would benefit those currently getting lesser pension and will on par with any disabled person without the feeling of being subjected to discrimination.

Apart from this, the scheme under Persons with Disability (PwD) is provided with need based aids – callipers, tricycles, hearing aids, etc and Self Help Groups (SHGs) for PwD are formed for economic sustainability of the affected individuals and their families. A group of 5 to 10 persons with disabilities can form SHG, unlike the women SHGs, which mainly focus on economic activities. While our programme targets the persons with disabilities in villages living with low self-esteem, playing a limited role in the society or family, little or no access to welfare schemes, lack of awareness of their rights, etc, and help them to get financial support for initiating viable livelihood options in the form of interest free loans from banks with a matching grant from IKP. Eligible persons affected by leprosy in many villages are also apart of SHGs and have benefitted through the government schemes through a combined effort by the Government and NGO partner in this district.

vi) **Mr. Chandra Sekhar Raju,** Project Director, District Rural Development Agency, East Godavari district.

In East Godavari district, DRDA is in the process of consolidating, developing and empowering the people with disabilities through SHGs and had conducted special SADAREM[3] camps for issuing disability certificates and disbursement of pensions. The disbursal of pensions has been linked to their Aadhar card and credited to their bank accounts directly and this has helped to prevent fraud and avoid bureaucratic hurdles. As a practice, the biometric data on the fingerprints of all beneficiaries are recorded and validated for receiving the pensions as a security measure and to foil any malpractice. Even with this fool proof system, it has become a bane for some persons affected by leprosy either who have lost fingers or hands as well as persons affected by leprosy who are immobile due to disease to benefit from the welfare scheme.

Interaction with Project Director - DRDA, East Godavari

As a best practice, the District Collector had issued orders to conduct special camps wherein this special category of persons affected by leprosy could register any of their able bodied family members as a nominee to receive the pension on their behalf by authenticating their fingerprints. Assured to bring all the people with disabilities including those due to leprosy living in the district and will be assessed for disability status by promoting village level camps to enrol them under this scheme. Willing to extend all cooperation and invited suggestions to improve the reach by DRDA and to present any issues being faced by persons affected by leprosy as an NGO working with people affected by leprosy in the district.

"Living with dignity"

Gangamma, 65 years old, a widow, a victim of leprosy for more than 40 years, living in a village and dependent on her son's family for all her personal and health needs. She attends POID camp regularly at the PHC conducted by RISDT on her own and if need be visits their Referral Hospital at Kathipudi in East Godavari district.

". . . ever since my husband expired 10 years back, I had to depend on my son for my livelihood and my family considers me a burden. Thanks to RISDT, who helped me to register under SADAREM scheme and now I am receiving Rs.500 as monthly pension since 6 months . . . even this meagre support in my present life has come as a boon for me. Now I don't have to beg for money from my son or daughter-in law to go the hospital or to fulfil my small personal needs. Now I am living with dignity . . ."

5.2 Project level officials - NGO partners

i) Greater Tenali Leprosy & Education Scheme Society (GRETNALTES), Guntur district

Greater Tenali Leprosy Treatment and Education Scheme Society (GRETNALTES), a registered NGO established in 1981, was engaged in leprosy relief work based on SET pattern under vertical NLEP in 3 districts of Andhra Pradesh. The NGO is also managing a 32 bedded referral hospital in Guntur district since 1986 with established microscopy centre, operation theatre and MCR footwear unit. The NGO provides a comprehensive leprosy services to people affected by leprosy including reconstructive surgery and special MCR footwear. GRETNALTES is one of the NGOs supported by FairMed in Andhra Pradesh since its inception. It is also one of the NGO who implemented DISPEL project by engaging leprosy trained health personnel in Guntur district since 2000.

"*All the staff members of GRETNALTES are well trained and experienced to provide excellent POID services, majority of them are with the NGO for more than 15 years. With all diligence we initiated the POID project and the goal was to provide quality POID services and strengthen the existing government general health care system to own the processes for providing POID care by building their capacities. The mobile team of NGO has implemented the POID project in the district, while the core team coordinated the camp activities in collaboration with the Govt. of AP. The multi-sector approach used in POID project has enabled the project team to deliver holistic services to a large number of persons affected by leprosy in the district.*

Able to achieve success to an extent as trainings were conducted to APMO/DPMO, MOs, ASHA supervisors, ASHA workers, etc in the district. Additionally, involving the health personnel of NLEP and PHC during the mobile POID camps, reminding and motivating them during their monthly review meetings at their respective health centres was not enough to get the desired change. There is need to promote concerted dialogue and advocacy for establishing stronger communication link right from the state level to the district and sub centre level to support his POID project. ***Through the back stopping support provided by FAIRMED team, this communication route has been established that has greatly helped to reinforce the significance of giving priority to NLEP activities by the GHC system****, however the challenges at the implementation level will remain unless and until there is a clear policy directives by the Government.*

The prospect that the POID activities can be ***sustained by the health system with their own resources seems unlikely.*** *In order to achieve specific impact, the POID project needs to be continued for 2 or 3 more years with a renewed strategy and supported by FairMed with the same quantum of funds."*

ii) Rural India Self Development Trust (RISDT), East Godavari district

Rural India Self Development Trust (RISDT), a registered NGO started leprosy control work since 1983 in a few selected districts of Andhra Pradesh. The NGO is providing a wide-range of rehabilitation services to people affected by leprosy including livelihood support. The NGO has a well equipped 60 bedded Referral Hospital with operation theatre facilities for performing reconstructive surgery and also MCR footwear making unit. This NGO is supported by FairMed and was one of the key partner in implementing DISPEL programme in the districts.

"*RISDT has best facilities – infrastructure and its biggest strength of all is dedicated, committed and experienced staff providing quality services to people affected with leprosy and their families. RISDT has been working in close coordination with government at all levels since long and* ***through POID project this relationship has been more strengthened****. Past relationship with government has helped in achieving very good results, in spite of many challenges encountered in implementing the POID project. At least 70% of the PHCs have shown greater involvement in the POID project through the concerns expressed by the Project team. Just to ensure need based distribution of self care kits to persons affected by leprosy with wounds in the foot by the PHC itself was difficult. Frequent transfer of trained health staff and allocation of funds for requisite number of MCR footwear by the state to the districts were some of the challenges.* ***The number of MCR footwear supplied by the NLEP is inadequate, though it was provided to all needy persons affected by leprosy in the district through this project.***

The POID project has made great strides in terms of reaching POID services to the needy persons affected by leprosy with disabilities at the PHC level in a comprehensive manner. *However there is a policy lapse to involve the GHC system in providing POID services under NLEP in the district. The supervisory visits by the technical team of FairMed had some effect in changing the attitude of NLEP staff in the district. In order to motivate and as a token of recognition for their efforts and contribution to NLEP / POID project, some of the best performing staff – MOs, Nurses, ASHAs were felicitated, which helped to get desired level of response and cooperation from the staff in addressing the needs of persons affected by leprosy.*

Before transitioning the project, there is a need to organize two day sensitization training for all key stakeholders from the PHC/CHC/UHCs to reiterate their responsibility in providing POID services, and transfer the ownership of the project. It was planned but could not undertake due to political unrest. The Project team will provide technical and mentoring support through planned programme. Any change in the present strategy to be followed by a phase wise handover plan that constitutes capacity building of health personnel in the districts facilitated by FairMed and supported by NLEP, establishing good coordination mechanism between different sectors and ensure adequate resources for POID services from the Government.

5.3 Peripheral level health personnel at the PHC / CHC / UHC

i) Profile of the NLEP personnel interviewed

16 leprosy trained personnel working under NLEP unit (8 in each district) in these 2 districts were interviewed. This includes 2 members of District Nucleus Team, both Leprosy Physiotherapy Technicians; 8 Deputy Para Medical Officers (DPMOs) and 6 Assistant Para-Medical Officers (APMOs). All respondents are male except one female APMO in East Godavari district. The year of service in NLEP ranges from 18 to 32 and the mean years of service is 26.

ii) Profile of the GHC personnel interviewed

19 general health care providers including 1 SPHO, 15 Medical Officers and 3 nurses were interviewed in both the districts. The years of service of the health care providers ranged from 1 month to 14 years. Besides, 6 focussed group discussions were held among groups of ANM, ASHA workers and persons affected by leprosy. The age and duration of disease of the persons affected by leprosy ranged between 14 to 60 years and 1 year to 40 years respectively.

iii) Assessment of training to NLEP & GHC personnel in POID services

Strategy:

Although the project activities commenced in 2010, the training of key stakeholders in the districts were done only during 2011-12. These training were conducted by the respective Partner Organization in collaboration with the NLEP unit of the district. Special training curriculum was developed by the Partners team under the guidance of Technical expert from FAIRMED. Most of the NLEP (APMOs and DPMOs) and PHC / CHC (GO-POID) personnel have undergone one day orientation training on POID in leprosy during 2011-12.

Findings and Observations:

- ***Refresher training*** organized by FairMed team for the NLEP staff on the new NLEP guidelines as well as the DPMR operational guidelines in the districts did not resulted in improving the skills especially on nerve function assessment and reaction management.
- One day training on POID organized by NGO partners for the NLEP and GHC personnel was inadequate and ***had less practical demonstration*** on the methods of NF assessment.
- The training curriculum developed by the NGO partners ***lacked linkages with the NLEP initiatives*** and did not focussed on the outcome of the training.
- Despite training and long experience in managing leprosy cases, the NLEP personnel still ***lack required skills to perform nerve function assessment*** of the leprosy cases.
- Following ToT training on leprosy conducted by NGO partners for ASHA facilitators did not ***have a cascade effect to train the rest of ASHAs*** in the districts.

6. ACCOMPLISHMENT OF OBJECTIVES AND ACHIEVEMENTS

6.1 Analysis of project objectives and results

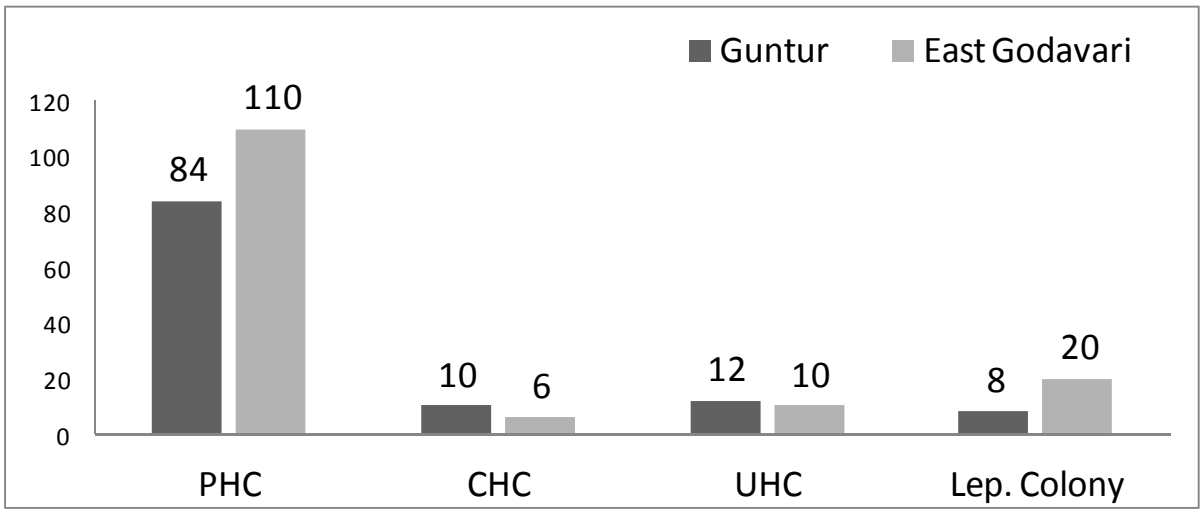
The overall objective of POID project is intended to complement, support and add value to the NLEP programme by providing POID services to all persons affected by leprosy at PHC level in Guntur and East Godavari districts of Andhra Pradesh. The specific objectives of this project are expected to achieve the following results:

a) The Primary Health Care system in POID is assured

Strategy:

The POID camps conducted by the mobile team of NGO Partners at all GHC centres (PHCs + CHCs + UHCs + Leprosy colonies) in the districts once in 3 months. Details of GHC centres where the persons affected by leprosy provided POID services though camps in the districts are given in chart 1.

Chart 1: Details of GHC centres and leprosy colonies reached in the districts



Findings and Observations:

- All the POID services that are provided to the needy persons affected by leprosy during the POID camps by the project team were not sustained by the NLEP or PHC staff on the days other than the camp as they lack technical skills and required resources under NLEP.
- Although this project have visibly motivated the NLEP workers (APMO & DPMO) to retain interest in the POID activity, it had minimal effect among the health personnel in the PHCs particularly in changing their attitude towards persons affected by leprosy and in treating them on par with other diseases.

- The POID camps reached POID services to a few leprosy cases with disabilities in the area and involved limited number of PHC workers (GO-POID and ASHA) that lacked intensity of its purpose and remained a 'standalone' intervention with minimum follow-up activities.
- The nerve function assessment (NFA) and recording the disability status of all persons affected by leprosy is regularly done by the project team, ***but the quality of NFA done by the APMO is in a rudimentary state and often there was no follow-up assessment***.
- None of the GO-POID interviewed performed NFA of new leprosy cases reporting to the PHC even though they have received one day training on POID at the respective centres of the NGO Partners in the districts.

b) Self care to prevent disabilities and impairments is reinforced

Strategy:

One of the highlight of POID project is the active involvement of the persons affected by leprosy in practicing self-care by improved procedures and the availability of the tools for self-care at camps. Group counseling was provided to persons affected by leprosy with disabilities and deformities and taught safety measures to overcome the damaging effects and protect their limbs and eyes from injuries.

Findings and Observations:

- Self-care has been demonstrated to be an effective means of preventing secondary damage among the persons affected by leprosy with NFI in limbs and eyes under this project.
- Self care of an individual needs family support, of the few family members interacted with they seemed to be less involved, untrained, to attend to the needs of persons affected by leprosy. ***It is also observed that the new leprosy cases, specifically young individuals lack clarity on preventive aspects of self care, which needs to be emphasized***.
- Although the persons affected by leprosy were encouraged to practice self care measures regularly, no mechanism to ensure compliance in place. A little convincing documented evidence exists that self care measures has contributed to changes in the disability status resulting in better health outcomes of persons affected by leprosy.
- Dressing kits are being provided from the project but accessing the same subsequently from the PHC/UHC seems to be difficult for the persons affected by leprosy as one of the major reasons being insufficient stocks of gauze, bandage, antiseptic creams, etc at the GHC centers. This could be due to lack of sensitivity on the part of the health department on the whole and particularly the respective health centers towards the needs of persons affected by leprosy and miss out on this important activity while planning, budgeting and indenting the supplies. Supply of dressing kits to the leprosy colonies is being met from the NLEP funds through the ADHMO office, which at times is not sufficient.

c) Access is provided to POID services for immobile and needy persons.

Strategy:

A few persons affected by leprosy who are immobile due to severe physical disability were provided POID and rehabilitative services at their doorstep in the village or in the leprosy colonies by the mobile team. Alongside monthly ration is provided to these immobile and needy persons under government (AAY) scheme and with the support from other NGOs in the district. The family members were encouraged by the project teams to give psychological support to the immobile and needy persons affected by leprosy in the districts.

Observations:

- It is highly appreciated that the POID teams have reached POID services at their doorstep of immobile and needy persons affected by leprosy by the NGO partners. However the family members need to be motivated to take care of the physical and health needs of the persons affected by leprosy.
- Much has been done to rehabilitate such immobile and needy persons affected by leprosy and it is suggested that a coordinated effort is to be made with the NGOs providing general and multi rehabilitative services including the Government agencies.

d) The community participation in POID is improved

Strategy:

The involvement of "ASHAs" through community's external actions, particularly in the areas of self care practices is envisaged as community participation. ASHAs were involved in mobilizing the persons affected by leprosy for the POID camps. The strength of this initiative is that the community fully respects the contribution of the NGO partners in delivery of quality leprosy services including medical care through the POID camps.

Observations:

- Actions in pursuit of the community mobilization and empowerment for POID were not confirmed, except motivating a few community volunteers in the districts for group session.
- The contribution of ASHAs propelled as an ***alternate strategy for 'community involvement' did not offer the desired results*** in promoting the compliance for POID services and follow up of target beneficiaries at the village level.
- The support and ***involvement of Village Health & Sanitation Committee (VHSC)*** in addressing the health concerns of persons affected by leprosy is not evident in any of the PHCs visited in both the districts.
- ***Educating the community on the scientific facts about leprosy to create awareness and promote early new case detection is absent, which is crucial to prevent disabilities***.

e) The development of project is assured and is continuously monitored and evaluated

Strategy:

The technical monitoring of the project was jointly done by the technical advisor (Dr. S. A. R. Krishnan) and the National Technical Coordinator of FairMed (Dr. Akshaya Kumar Mishra) on quarterly basis in both the districts. Besides, one mid-term evaluation was done by internal consultant - Dr. S. A. R. Krishnan (December 2012).

Observations:

- On analyzing the 7 reports on 'Back stopping' exercise, it was noticed that the feedback report was focussed on '***activity monitoring' rather than 'process monitoring'***.
- One of the limitations of effective monitoring is the inadequate data collection and ***unavailability of qualitative data*** especially from the NGO Partners, other than activity (status) report.
- Most of the findings including the challenges identified (SWOT analysis) of the internal evaluation done by a CBR consultant from FairMed, Switzerland were confirmed during the course of this end evaluation.
- The ***project steering committee as proposed was not formed*** as well as the engagement of Project Coordinator did not materialize due to anonymous reasons. There was no monitoring tool developed despite the recommendation of the mid-term evaluation.

6.2 Key outcomes of POID Project

According to the project document, the following **'indicators'** were proposed to measure the key outcomes of this project:

1. *Disability grade 0 cases among new cases remain on grade 0;*
2. *Disability grade 1 cases among new cases remain on grade 1 level or improved to grade 0;*
3. *The number of disability grade 2 cases among new cases is reduced (proportion);*
4. *The ulcer development among 'old cases' is reduced sustainably (proportion).*

The above indicators were analyzed in terms of drawing inferences and evidences from the data on 'line listing' of the beneficiaries maintained by the NGO partners in order to measure the key outcomes of the POID project. The source of data as given in the 'line listing' falls short of performing any qualitative analysis, therefore it was decided to make a formative assessment of the outcome.

The WHO disability (Impairment) grades are recorded for all new leprosy cases at diagnosis under NLEP, however it is not a sensitive tool to monitor changes in disability status following interventions during or after MDT[4]. The EHF score is part of the assessment form (P II) and

being recorded at initial and follow up at varying period of intervals. Few evidence based studies advocate that the reliability of either, WHO disability grading or EHF score, depends on operational definitions that are often ambiguous and provide little scope to measure the outcome of the disability status in individual leprosy cases[5]. Therefore the relevance of using these as an outcome 'indicator' is not an appropriate measure to monitor the POID programme.

Despite the above elucidations, an attempt was made to examine the 'line listing' of all leprosy cases registered under the POID project to measure the outcome based on WHO disability grading. The details of leprosy cases registered under POID programme (Baseline assessment) in the districts are given in Chart 2 & 3.

Chart 2: WHO Disability grading of leprosy cases

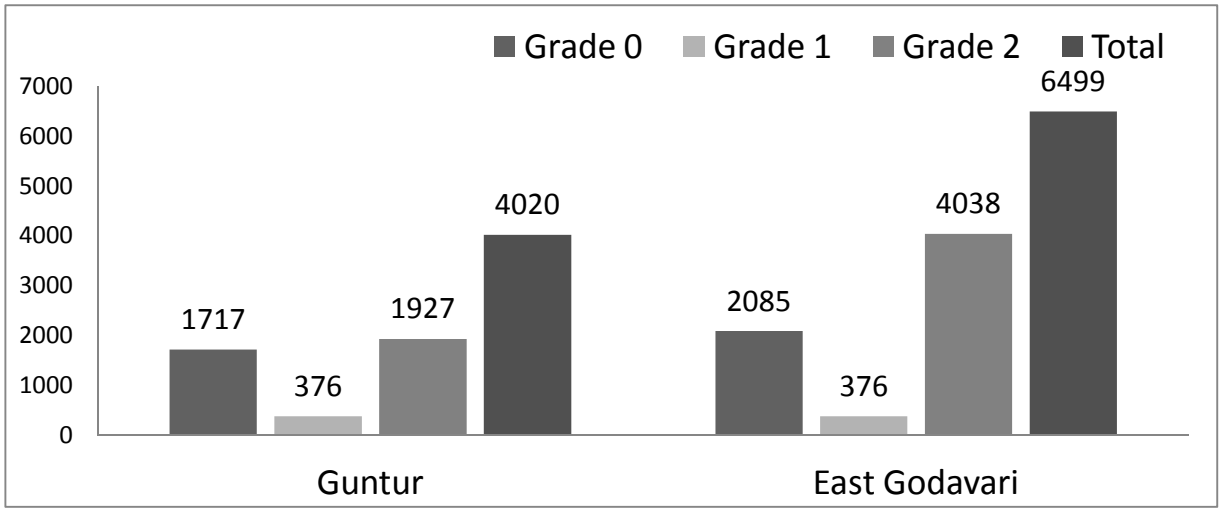
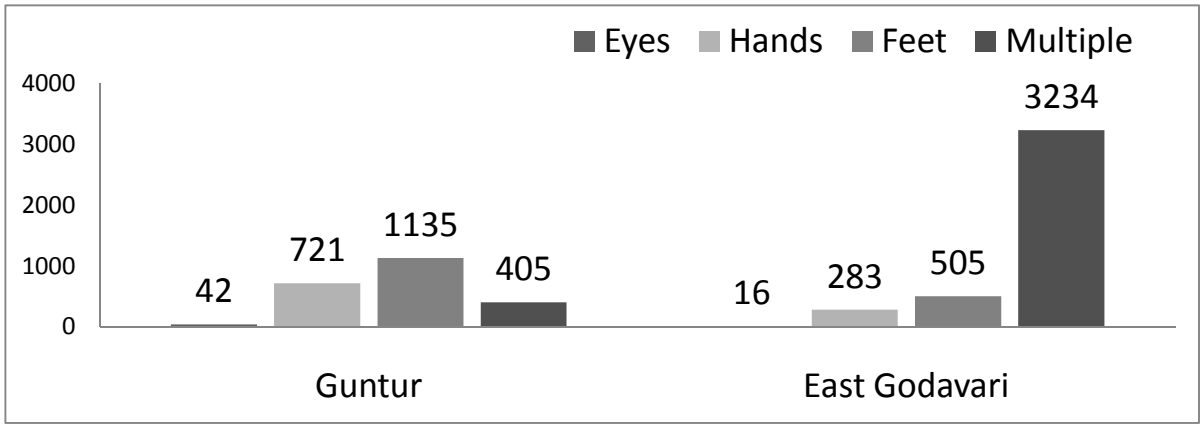


Chart 3: Leprosy cases with Grade 2 disability - Limb wise



Findings and observations

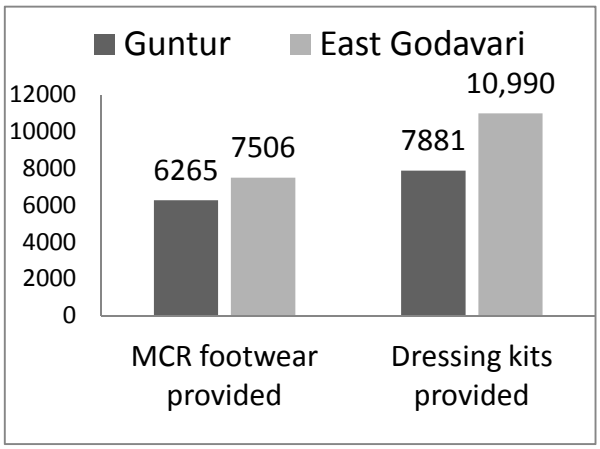
- The line listing present only the WHO disability grading of 1 and 2, limb wise at the time of registration (Baseline assessment) and **follow up grading is not available in the template**.
- The data on leprosy cases registered with grade '0' is not a part of the line listing template, however it was included later since 2011. Moreover the existing line listing data does not provide any indication of the measure on change in impairment and disability status.
- There is a perceptive error in assessing the nerve function status periodically in those persons affected by leprosy when NFI has already occurred before the diagnosis of leprosy.
- Different procedures and guidelines were followed in the districts for assessing and recording the nerve function status of all new leprosy cases without disabilities and deformities (Grade '0') defies possibility to analyze the data.
- No data available in the line listing to substantiate the number of persons affected by leprosy with NFI at the time of diagnosis but developed new NFI during MDT and after their release from MDT.
- Only a few leprosy cases found to have developed new NFI during the course of treatment with MDT and were put on a fixed regimen of steroid therapy as recommended by NLEP.

6.3 Effectiveness of the strategies adopted under POID project

Both the NGO Partners have long standing experience in implementing leprosy control activities including provision of appropriate POD services to those persons affected by leprosy with disabilities. The strategies adapted by the NGO partners have ***undoubtedly endeavored to guarantee the availability of POID services at the primary level with a view to make a difference and improving the quality of life of the persons affected by leprosy***. The strategy intervened in the areas of ***capacity building of general health care providers for the delivery of leprosy services have shown encouraging results***. The initial efforts of the POID project have involved and engaged persons affected by leprosy in their own self care and empowered them to realize their entitlements under various welfare schemes of the government. The process of promoting self help groups as an inclusive rehabilitation is expected to greatly contribute in the upliftment of their social and economic status of the persons affected by leprosy in future.

A total of 3,802 persons affected by leprosy with no disabilities (Grade 0) were assessed and monitored for possible nerve function impairment (NFI) through standardized clinical nerve function assessment (NFA) in these 2 districts under this POID project. Similarly, a total of 10,519 persons affected by leprosy with grade 1 and 2 disabilities and deformities were provided appropriate field based POID services in these 2 districts. 13,711 MCR footwear and 18,871 dressing kits were provided to needy persons affected by leprosy through the POID Project in both the districts.

Details of MCR footwear and dressing kits provided in the districts



6.4 Synergies and coordination mechanisms

This POID project has adopted a holistic approach to deliver leprosy services that is aimed at addressing the medical, physical and economical needs of persons affected by leprosy. ***Such an all inclusive strategy have helped and supported the persons affected by leprosy while ensuring that their social well being is not sacrificed for the benefit of the population***. The NGO Partners have identified and created linkages with other government departments of social and development sector in both the districts***. This initiative has benefitted a large number of persons affected by leprosy through the welfare schemes meant for under privileged section of the society.***

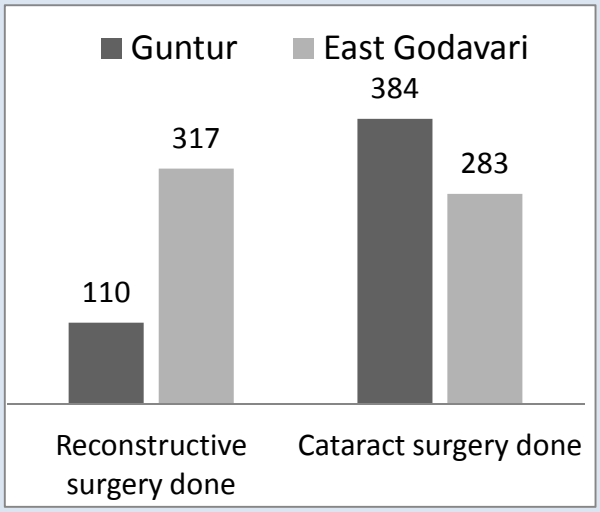
The NGO Partners has ***established good coordination with the state and district level health officials of the Government***, State Leprosy Officer, District Medical & Health Officer & Additional District Medical & Health Officer (AIDS & Leprosy) and Special Public Health Officer (SPHO) and drawn their support in coordination with the peripheral level health functionaries. The core team of the project has maintained cordial relations with the NLEP and GHC staff for implementing the POID activities in the districts. However, the synergies made have not resulted in influencing the policies and programmes of NLEP and the project has not gone beyond the role of a complimentary service provider.

- **Cataract surgery for persons affected by leprosy with eye problems**

Cataract is one of the common causes for blindness in leprosy and the risk increases with advanced age, intraocular inflammation due to reactions (ENL) and presence of longstanding grade 2 disabilities in eyes. Therefore, it is imperative to recognize the vision threatening conditions due to leprosy and other causes and intervene timely and appropriately to prevent blindness. This project has coordinated with the National Programme for Blindness Prevention

and availed the ophthalmic care and services for the needy persons affected by leprosy. This has enabled 667 persons affected by leprosy to retain the vision, which is essential to prevent any injury or damage to their insensitive hands or feet. The details of persons affected by leprosy underwent cataract surgery and reconstructive surgery for the correction of deformities in both the districts is given below.

ROLE OF SURGERY IN PREVENTION OF DISABILITY AND DEFORMITIES IN LEPROSY



Strategy:

Surgery plays an important role in prevention and corrections of visible deformities thereby alleviate the social stigma. Both the NGO partners have pre and post operative facilities and infrastructure for performing leprosy reconstructive surgery at their centres, which is recognized by the Government of Andhra Pradesh as well as facilitated cataract surgery for the needy persons affected by leprosy at the GHC centres in the districts.

Findings and observations:

- In coordination with the blindness prevention programme of the government, the vision was conserved in large number of persons affected by leprosy through cataract surgery.
- The outcome of reconstructive surgery in a few leprosy cases were not successful as observed during the field visits in Guntur district, while it is fine in East Godavari district.
- Possible reason could be the difference in surgical techniques and the experience of the surgeons for correcting the visible deformities that require minimal post-operative care.

Recommendations:

- Any surgical intervention should guarantee improved functional, economical and social status of the persons affected by leprosy through long-term post-operative care.
- Need to undertake a long term assessment of all cases underwent surgery in the districts.

- **Monthly pension for needy persons affected by leprosy**

People affected by leprosy may lose their employment because of their disease, the disabilities associated with it and negative attitudes of employers. As a result, they lose the means of income to support their families and often the respect of their communities. The synergy made with the DRDA officials in the districts who have extended economic assistance of Rs.500 to 3207 persons affected by leprosy by way of regular monthly pension. This support can alleviate the financial burden to some extent and restore self-esteem of the persons affected by leprosy.

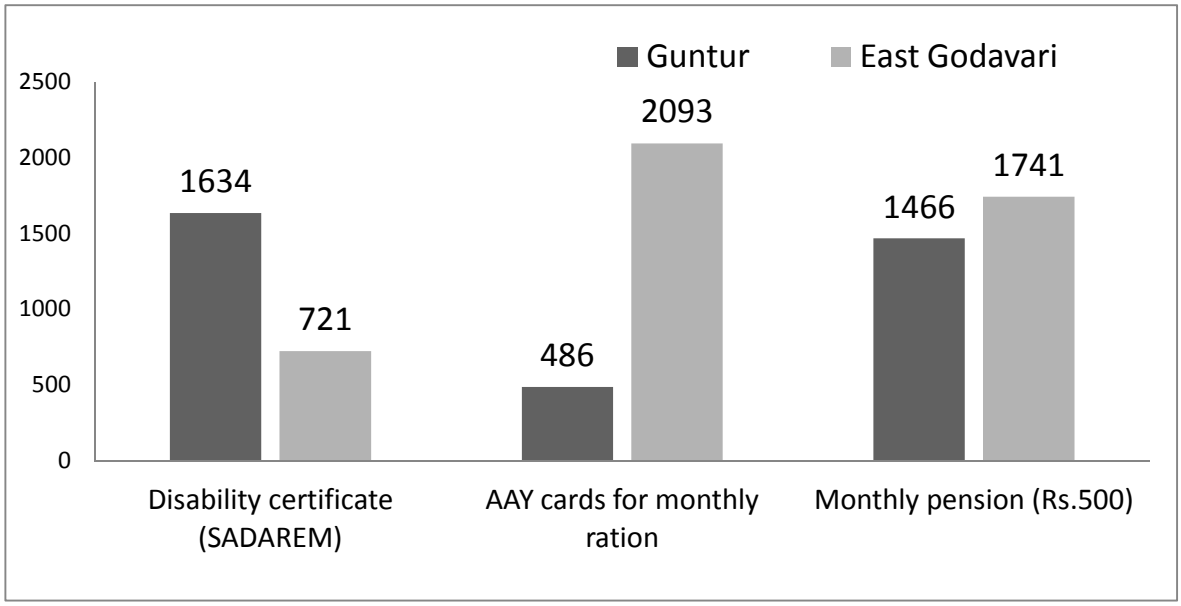
- **Disability certificate for persons affected by leprosy with disability**

This project has ably mediated with the concerned officials of the state government in the districts to issue 'disability' certificate to the persons affected by leprosy in order to avail facilities and concessions viz. Reservation in job, travel concession, soft loan for entrepreneurship development, scholarship, income tax rebate, age relaxation in employment etc. 2,355 persons affected by leprosy with disabilities and deformities were issued 'disability' certificate in the districts through SADAREM in both the districts. Standard guidelines and tools mentioned in the notification have to be used in evaluation of disability for issuing proper certificate.

Government of AP is implementing Indira Kranthi Patham (IKP) under Society for Eradication of Rural Poverty (SERP) to enable the poor to improve their livelihoods and quality of life through their own organizations. The department of rural development, has launched a **Software for Assessment of Disabled for Access Rehabilitation and Empowerment (SADAREM)** in close collaboration with departments of disabled welfare, Medical & Health and NIMH to create a dynamic web enable system for comprehensive access, rehabilitation and empowerment, through automation, capacity building, assessment of persons with disabilities (PWDs) and maintaining decision support system. Necessary orders are issued to take up assessment of all the persons with disabilities including leprosy to generate Medical Board certificates and ID cards.

The certificate would be valid for a period of five years for those whose disability is temporary, while the validity is for lifelong in case of permanent disability. However the minimum degree of disability should be 40% in order to be eligible for any concessions / benefits from the Government. In view of the constraints in terms of physical and financial, the government has earmarked 40% disability as a cutoff to be eligible for various facilities & concession. It was noted that the procedure on assessment of disability percentage was not proper and majority of the persons affected by leprosy with visible deformities (Grade 2) in any one of the limbs or eyes were given less than 40% disability status, thus making them ineligible for the welfare schemes given by government for the PWD. However, there is a need to issue clear guidelines by the Ministry of Health & FW. More details on the guidelines for issuing disability certificate are given in Annexure 3.

Chart: Details of socio-economic assistance given to persons affected by leprosy



Antyodaya Anna Yojana (AAY) is a Government of India sponsored scheme launched in December 2000 to help the 'poorest of the poor' by providing 35 kilos of rice and wheat at Rs.3 & Rs.2 per kilograms respectively as a guarantee for food safety[6]. 2,759 persons affected by leprosy who fall in the category of 'below poverty line' (BPL) have benefitted by this scheme in both the districts. Several persons affected by leprosy who are above the 65 years of age and have no regular means of subsistence from own sources of income or other sources were given Rs.200 every month as old age pension under the National Social Assistance Programme (NSAP) of the Government of India in the districts[7].

6.5 Role of key stakeholders and their contribution in POID project

a) Roles and responsibilities of the NLEP personnel:

The APMOs are qualified leprosy workers and is responsible for implementing the NLEP activities at the PHC level and attend the PHCs once a week while doing field work on rest of the days in the week including community level IEC; undertaking special activities such as POD camps in leprosy colonies and organizing special search activities with search teams. APMO maintains the NLEP records (LF-1; LF-2; LF-3) and compiles the monthly NLEP reports for the respective PHCs (LF-4 & LF-5) and submits the same to the designated DPMOs who coordinates with the PHCs at the sub-district level. APMO also attends the monthly meetings at PHC level and updates the PHC staff on the leprosy situation and orient them on leprosy.

The DPMOs are responsible for the supervision of the APMOs at cluster (Group of PHCs) level and responsible for the overall supervision and reporting of NLEP activities. DPMOs will attend the district level meetings and submit the NLEP reports of respective clusters. DPMOs also coordinates with the District Nucleus Team in the district and conduct trainings of health personnel including ASHA at PHC level.

b) Roles and responsibilities of the GHC personnel:

i) Medical Officer of PHC / CHC / UHC

The medical officers (MOs) are responsible for examining, diagnosing and prescribing treatment for new leprosy cases, including management of lepra reaction cases. 12 (80%) out of 15 MOs interviewed had undergone two to four days training on treatment and management of leprosy organized by the ADHMO of respective districts. 3 (20%) out of 15 MOs interviewed in both the districts have joined in the last two years so did not receive any formal training on leprosy and some of them have not even seen a single leprosy case at their health facility. Except for few MOs, confirmation of diagnosis and treatment with MDT are done by NLEP staff – DPMO / APMO. Wherever the DPMO / APMO position is vacant in a particular PHC, the NLEP personnel from adjoining PHCs are entrusted to provide leprosy services on a particular day in a week. At the same time, MOs who undergone orientation training in leprosy are confident in management of reactions among new cases for which there are sufficient stocks of Prednisolone drugs. 75% of the MOs interviewed were not aware of the incentive protocols / guidelines for ASHAs and did not have clarity whether any one of their ASHAs ever had received any cash incentives for their role in NLEP. All (100%) the MOs interviewed were not aware about the provision of MCR footwear through NLEP funds, nor they were contacted anytime by the ADHMO regarding any data or indent for MCR footwear requirement.

ii) Staff nurse of PHC / CHC / UHC

The role of nurse is to provide counselling and medical treatment for leprosy and the role of ANM is to provide follow-up services, dressing of wounds, provide counselling to ensure adherence to treatment while ASHA along with ANM carry out follow-up of all new leprosy cases (active) under MDT, identification of suspect and refer to PHC for confirmation of diagnosis and treatment. Sole wound management is primarily being done through the POID camps and during non-camp days neither the persons affected by leprosy are given dressing material by PHC or by the NLEP staff. Except few nurses and ANMs, their involvement in wound management is very rare. Most nurses in PHCs were not trained in filling the leprosy treatment records and preparing NLEP reports in the absence of any concerned NLEP staff.

iii) Government Officer for POID (GO-POID)

The ADMHO in these districts had officially designated one senior staff of PHC – Multipurpose Health Supervisor (MPHS) or Health Education Officer (HEO) - as Government Officer for POID (GO-POID) who are made responsible for NLEP activities in the area. These GO-POIDs were given one day training on POID including on the methods of nerve function assessment (NFA) by the respective NGO partners at their centres. However, it was learnt that about 20% to 30% of the PHCs / CHCs do not have GO-POID. The supportive medicines for sole wound management and dressing materials provided to the leprosy cases during the POID camp is solely borne by the NGO Partners.

iv) Accredited Social Health Activists (ASHA)

ASHAs are involved in identification and referral of leprosy suspects across the two districts, but have not received any formal orientation training in leprosy by the ASHA facilitators who were trained by NGO partners as 'Trainers', except sensitization on leprosy during their monthly review meetings by the DPMO / APMO. Both NGO partners have provided one day TOT training to ASHA facilitators who in turn supposed to have trained their ASHAs in the PHCs. Most of the ASHA said that identification of leprosy suspects is not a priority, with their ever increasing list of priority health services to be provided in the community. Most of the ASHAs interacted lacked clarity on the safety instructions to be conveyed, which include do's and don'ts to prevent disabilities among new and old persons affected by leprosy and were not confident on conducting nerve function assessment as a follow-up assessment after completing treatment. Majority of them also lacked clarity on the incentive protocols on identification and follow up of leprosy, while some of them have expressed the delay or non disbursal of incentives since many months.

v) Persons affected by leprosy – the 'right holders'

Majority have expressed that POID services are not available at PHC other than the POID camps except dressing materials for 3 or 4 days. All are satisfied with services provided at POID camps conducted by NGO partner. Few seek access to special services available at the Referral Hospital in the districts. Most of the PHC staff are non-responsive towards their general health needs. ***Many had received non-health related benefits like disability certificates, AAY cards, and educational support for their children, etc through the efforts of NGO partners.***

"I was surprised when one of my regular patients was diagnosed with leprosy. Every time she would complain 'itching' problem, until she showed a big patch on her back during special survey. Even now whenever she comes to PHC for treatment, she prefers to keep her condition be kept confidential. Still there is stigma in the community, which needs to be addressed. It is very much possible to provide POID services to the leprosy patients through the existing staff and facilities at PHC, but less emphasis is given to leprosy" – *Medical Officer, PHC, Guntur district*

6.6 Community based initiatives and community involvement:

WHO introduced the strategy of community based rehabilitation (CBR) to enhance the quality of life for people with disabilities through community initiatives to support the rehabilitation of people with disabilities in their own communities. However, due to stigma many CBR programmes failed to recognize people with leprosy-related disability as equal members of the community requiring rehabilitation[8]. In 2006, WHO has developed regional strategies related to community based initiatives (CBI) to create development policies and directions that are supportive to health, community empowerment and local governance to ensure health equity and quality of life through community organization and mobilization.

- **Community involvement and actions**

The paradigm shift from 'individual based health care' to 'public health approach' based on the concept of 'CBR' as demonstrated through this POID project has proved to be effective in reducing the disability burden due to leprosy in the communities considerably. While, the self-help group (SHG) is a strategy for dealing with the 'livelihood' component of CBR, the self care groups (SCG) can be termed as an 'empowerment' component of CBI. Both these strategies can be very effective in helping persons affected by leprosy with disabilities and in promoting participation and inclusion in societal mainstream. In a way this POID project has achieved its objective to a greater extent by improving access to physical and socio-economic rehabilitation services for the people affected by leprosy who are economically weaker, together with other community initiatives thereby ensuring their dignity.

- **Formation of Self Help Groups**

This project has encouraged the persons affected by leprosy to enter the mainstream livelihood by forming SHGs in the villages along with people with disabilities due to causes other than leprosy in both the districts. This is a best practice and implicit that the outcomes in the form of entrepreneurship, increased incomes and enhanced dignity are most visible at the well managed SHGs as seen in Guntur district. However the members of the self help groups are limited and they lack organizational skills in executing and managing profitable enterprises that have withdrawal effect in the long run. Many of the family members and persons affected by leprosy are joining as members of SHGs in their respective area and are receiving hand holding support through the concerned field level coordinators of IKP. At the same time, there are no successful SHGs amongst the leprosy colonies, except that the able bodied female members of persons affected by leprosy families are part of the existing SHGs***. It has been observed that NGO Partners in both the districts lacked specific skills in formation and empowerment of SHG groups. It is suggested that these SHGs can be encouraged to play an advocacy role with the government and take part in the health and development activities concerning the people living in their own village.***

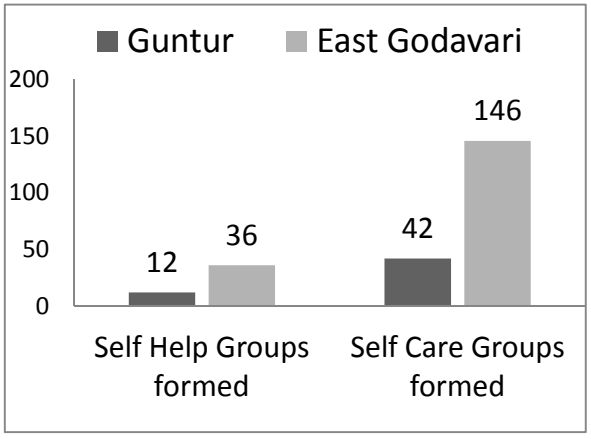
	
Discussion with the Self Help Group members	Felicitating a women affected by leprosy

As the SHG movement has been strongly advocated by the government, it is suggested that the NGO Partners need to play a facilitator role by ensuring that persons affected by leprosy become part of existing SHGs and are able to access various schemes, ensure that they continue to be active members of their respective groups, support them in planning and proper utilization of the interest free loans, which would make them financially sustainable.

- **Formation of self care groups**

In addition, the project also made an attempt to form "self care groups" at the village level with the help of Community Volunteers – *a person affected by leprosy identified by the team of NGO Partners, who is influential, communicative and motivated* – in order to assist the peers in non-health needs (socio-economic rehabilitation) and organize group therapy for promoting self care practices at village level. However, due to inadequate motivation of the Community Volunteers and the imperative local socio-cultural issues, this activity was practiced sporadically and could not be proliferated widely. It is suggested that this activity could be taken up as a component of CBR, while planning expansion of the project in the districts.

Details of self help groups and self care groups formed in the districts



6.7 Strengthening of the local health systems

The Project has in ***several ways utilized the resources available*** in the General health facilities for providing POID services such as medicines (analgesics, antibiotics and anti-inflammatory drugs) to the persons affected by leprosy. It was expected to increase the responsiveness of health personnel at PHC / CHC to provide POID services as an integral part of their activity. ***It must be noted that early detection and treatment of NFI can be practical and effective only by the peripheral staff of GHC centres are well-trained in proper nerve function assessment.***

The operational guidelines of Disability Prevention & Medical Rehabilitation (DPMR) programme, a critical component of NLEP (Issued by the Central Leprosy Division, Govt. of India in 2012)[10], clearly states the type of leprosy services that are to delivered at all levels of the General health system – primary, secondary and tertiary – on a regular basis. ***As a matter of fact, all the POID services that are provided through the camp are to be ensured under NLEP and adequate funds are being allotted by the Central Leprosy Division.***

The major strength of the POID project is the accessibility of referral services at the hospital centres managed by the respective NGO Partners in the districts with the support from FairMed. This has facilitated appropriate referral mechanism for providing specialized leprosy services such as skin smear facility, in-service wound management and reconstructive surgery.

6.8 Improving quality of life of persons affected by leprosy

It is a fact that the disabilities and deformities often create difficulties in economic and social aspects of the persons affected by leprosy thus affecting their Quality of Life (QoL). According to the World Health Organization (WHO)[11], QoL is the 'perception of the individual of his position in life, in respect to culture and in the value system in which he lives and in relation to his objectives, expectations, standards and concerns'. These parameters need to be analyzed from scientific and logical perspective considering both individual and community aspects[12].

The ultimate goal of this POID project is to strengthen the primary health care system with established and sustainable POD services as a practical intervention in the districts to enhance the physical activity that can improve the personal and social lives of persons affected by leprosy thus improving the QoL. The view point of this project is to empower the persons affected by leprosy by making them responsible to adopt safe practices that can minimize the effects of physical disability thereby giving them increased autonomy to participate fully as a productive member of the society. ***The Project has also tackled broader concepts of health through a focus on the prevention of disability and socio-economic rehabilitation efforts that can have direct effect in improving the quality of life of people affected by leprosy.***

6.9 Strengths and weakness of the Project Cycle Management (PCM)

a) Strengths of POID project:

- The field level practical demonstration of ***simple actions and procedures to persons affected by leprosy has helped to prevent and reduce the effect of disabilities*** and deformities as perceived by them and that has improved the compliance.
- Moreover this POID project has helped to sensitize and train the PHC staff including ASHAs to integrate leprosy control activities with other health services at the local level.
- The interactions and advocacy functions have strengthened the collaboration with other stakeholders, particularly from the social sector of the government (DRDA) and created great demand for integrated rehabilitation services for socio-economic mobilization and equal opportunities for people affected by leprosy.
- Additionally, this POID project has also improved the ***quality of leprosy services and ensured the availability of adequate MDT*** at the PHCs for all new leprosy cases as a matter of 'right to health'.
- One of the major strength of this POID project is the ***dedicated project team who are technically well versed with the management of leprosy*** as well as in implementing the project activities and the availability of hospital based leprosy care that provide comprehensive leprosy services and support the referrals from the PHCs.

b) Weakness of POID project:

- POID activities were more functionally incorporated into the NLEP than the GHC system, which require more technical skills and motivation on part of the health care providers. The presence of a trained GO-POID in a GHC facility made no difference in the involvement of other GHC staff in performing POD activities routinely.
- The POID project has contributed to health policy developments at state level to a very limited extent only and no contribution by NLEP in supporting the POID activities at PHC level has increased the dependency of part of resources from the NGO partners.
- Lack of appropriate monitoring system since the initiation of the project in September 2010 and the inadequacy of data in the templates for line listing defy any scientific analysis and possible correlation of the anticipated outcomes.
- Lack of collaboration agreement with the state government in the form of Memorandum of Understanding (MoU) that could have facilitated a forum involving both government health officials and NGO representatives for planning and decision-making in allocation of adequate resources for POID activities under NLEP.
- Barring one or two district level NLEP officials, the initial response to this initiative by NRHM in the state and district health department was mainly passive that has given a sense of uncertainty in sustaining the POID activities after completion of this project.

6.10. Sustainability and future prospects

The approach adopted under this POID project by integrating the delivery of POID services for persons affected by leprosy into basic health and primary care system through capacity building of the GHC personnel is the key to sustainability. One major constraint to integration is the capacity of basic health services to cope with medical and physical needs of persons affected by leprosy. Experts opined that the 'sustainability is fundamentally an ecological concept, but when applied to health care it tends to largely focus on financing[13].

The engagement of 'Back stopper' to provide technical guidance on the project management was useful in maintaining the quality of the services provided at the camps. The feedback report from the backstopping exercise has brought out several operational challenges to light that are identified as potential impediments in achieving the project goals. ***It was felt that the reports on back stopper exercise did not achieve its full potential as a tool for proposing concrete remedial actions and implementing measures.*** Nevertheless, the project implementation plan was revised based on the recommendations of the back stopper report and focused more on the nerve function assessment of all persons affected by leprosy.

The following projection on the results as observed over a period of time during the Back stopping exercise was 'impressive', however it lack guidelines and criteria that measure the change. Situation analysis or operational research as proposed in the project were not initiated and conducted during the entire project cycle period.

Summary of the past 6 POID Back Stop visit results in both districts:

Duration	Improved (I)	Same (S)	Worsened (W)
4th quarter, 2011	43/285=15%	200/285=70%	42/285=14.7%
1st quarter, 2012	17/245=6.9%	224/245=91.4%	04/245=1.6%
2nd quarter, 2012	72/203=35.4%	129/203=63.5%	02/203=0.98%
3rd quarter, 2012	09/210=4.28%	195/210=92.8%	06/210=2.8%
4th quarter, 2012	25/118=21.1%	89/118=75.47%	04/118=3.38%
1st quarter, 2013	62/150=41.33%	85/150=56.6%	03/150=2%

Following the recommendations of the 'Evaluation report on the Community Based Rehabilitation (CBR) aspects in the POID project, East Godavari and Guntur districts'[14], presented in August 2011, a revised Project Implementation Plan for the POID project was proposed in November 2011. The above referred report has brought out certain key issues for discussion and making policy decision by the FairMed to improve the project activities, develop monitoring mechanisms to measure concrete outputs, and ensure the follow-up of its recommendations, which was not implemented.

6.11 Lessons learnt and recommendations

- The project needs to strongly advocate increased participation of the health personnel at the General Health Care systems – PHC & CHCs in delivering POID services as well as encourage active involvement of ASHAs in promoting home based care.
- It may be argued that the ASHAs are not paid 'incentives' for delivering additional health services and therefore the project should consider drawing support from the available local funds available with Village Health & Sanitation Committee as well as Rogi Kalyan Samithis at village level.
- The trainings conducted for various categories of PHC and NLEP personnel in the districts need to be task specific and adopt participatory methodology.
- The assessment of indicators show that the shortfalls are also a result of the fact that the FairMed does not set valid goals and measurable targets to monitor the 5 project measures implemented under this POID project in these districts.
- Although specific actions to be undertaken by different stakeholders to implement these project measures are clearly defined in the project matrix, it did not set concrete targets and timelines for action.
- Moreover, the added value of this POID project had a limited effect on the strategy of NLEP at district and state level as process of the project is developed in a pilot mode.
- Since inception, the Government perceived this POID project as a NGO initiative. Therefore, FairMed in coordination with the NGO partners need to play an advocacy role to ensure that the state authorities initiate processes for institutional acceptance and responsiveness for this POID programme at all levels as an integral part of the public health system.
- Lack of community level action and enticing active participation of the community and groups including the person affected by leprosy in leprosy control activities, which needs to be addressed effectively with innovative measures in future. This can result in voluntary reporting of new leprosy cases early without any disabilities and deformities.
- In order to achieve this, FairMed can strengthen the core team of the NGO Partners with further leadership and management skills and make them more consistent through improved programme monitoring for realizing the set objectives and goals of this project.
- There seems to be a general responsiveness of district health officials in both the districts, but **if co-operation is not mandated from the state level officials, then it becomes a low priority and seems to be optional**.
- Astonishingly, it was learnt that there is no provision of funds for NLEP activities in both the districts as per the District Health Action Plan (DHAP) under National Rural Health Mission (NRHM) in the year 2013-14. Hence the project team should engage in consultation with the district and state level health officials and evoke response and support to replicate this initiative in all other districts through government resources.

a) General observations on POID services

- Surprisingly, a less proportion of leprosy cases under MDT were reported in both the districts who developed either acute or silent neuritis as a consequence of lepra reactions.
- An unusual observation was that even such incidental 'reaction' cases were referred to the NGO centres in the district for the management of neuritis.
- A few leprosy cases who developed muscle weakness due to neuritis (acute or silent) as a clinical event during lepra reaction were not treated with steroid therapy.
- Active or assisted exercises with the help of dynamic splints to restore the muscle strength were not practiced at the camps and such cases were rarely referred to the Hospital or Centre of the NGO Partners for physiotherapy.
- No scientific basis or any justification for assessing the nerve functions periodically of those persons affected by leprosy when the NFI has already occurred before the diagnosis of leprosy. Moreover, there was no data to substantiate the number of persons affected by leprosy with NFI who developed new NFI during MDT and after their release from MDT.

b) Assessment of comparable initiatives

To the best of our understanding, one model SALEM PROJECT[15] with similar objectives of AP POID project, an initiative by St. Mary's Leprosy Centre, a NGO in Salem district of Tamil Nadu during 2005-06 supported by Damien Foundation India Trust (DFIT). The methodology was identifying along with the district programme officer, a core team for planning and implementing POD in the district, and guiding the team for capacity building of peripheral staff in the Government health system to help people affected by leprosy living with disabilities take care of themselves. The project staff identified 1232 people with leprosy-related disabilities and trained them in self-care and distributed 847 MCR footwear in the district.

Follow-up assessments indicated that 86% were found to be practicing self care regularly and all the 239 general health workers were found to be actively involved, however this aspect need to be strengthened in AP POID project. The most important outcome of this project was the healing of plantar ulcers in 70% of people at the 1-year follow up, which was the same in AP POID project. It is projected that this model is sustainable because of the simplicity of the procedures and the involvement of all health staff, however its success depends on the clear guidelines for sustaining effective collaboration among all stakeholders.

Predictably, the elements and components of the POID project were nonexistence other than MDT service delivery as witnessed by the evaluation team and reflected by many of the stakeholders interviewed in 3 PHCs of West Godavari district as a contrast. There was no indication of any POID services available at the PHC level and no progress had been made towards integration of leprosy services into the GHC system in West Godavari district.

7. CONCLUSIONS AND PROPOSAL FOR FUTURE ACTIONS

Overall, the end evaluation has found visible POID project activity implemented by both the NGO Partners, using a standard approach in Guntur and Godavari districts. As such, the end evaluation clearly captures a lot of changes made through this POID project in several aspect of leprosy service delivery and is generally aligned with what both the Government and NGO partners consider a priority in health policy. However, it would be erroneous to assume that all of the negative actions identified by the evaluation can be directly attributed to the POID project as there are many incapacitating policy and institutional factors that have influenced the success or lack of it in achieving its goals.

It is likely that most positive actions occurred only at the primarily level because of the enthusiastic involvement of the Project staff in implementing the activities in the districts. It is imperative that early detection and treatment of NFI can be practical and effective means of achieving the objectives of this project and possible only by training and involving the health staff of PHC in proper nerve function assessment and monitoring the response as a part of routine leprosy services. Presence of a trained GO-POID in a GHC facility made no difference and not supported the involvement of other GHC staff in performing POD activities routinely at the PHC. As this POID project attempted to integrate the POID services into the weak and fragile infrastructure of GHC, which perhaps is a challenge to sustain the POID activity as an integral component of health service delivery by the GHC system. It is also essential to ensure long term benefits of reconstructive surgery in the aspects of improved functional, economical and social status of persons affected by leprosy through a scientific assessment.

Proposals for the future actions

The NGO Partners has longstanding experience in the field of leprosy control and can play the 'enabler' role by involving all key stakeholders in the GHC system in planning and implementing POID activities through capacity building in the districts. There is a need to put stronger processes in place to build active partnership with all stakeholders including the community and progressively transfer the ownership of POID activities to the GHC system in the districts in a phased manner. The NGO Partner should play a role in monitoring the POID activities along with the district level health officials in the districts.

It is also proposed that FairMed influence the Government at state level to share adequate resources and promote ownership of the project activities in the districts. It is further stressed that the FairMed has a mandate and working collaboration with the NLEP units in the state that could be utilized to engage the Government with specific work plans and enable joint monitoring of the project activities in the districts. FairMed can showcase the modalities of this POID project that is aligned with the priorities of NLEP in the state and national level.

8. PHOTO GALLERY

Group discussion with ASHAs in East Godavari district

Group discussion with persons affected by leprosy in Guntur district

Interview with the Medical Officers of PHC and NLEP

Interview with Medical Officer and persons affected by leprosy at Temporary Hospitalization Ward

Interview with NLEP (DPMO & APMO) and PHC (GoPOID) staff

Interview with NLEP (DPMO & APMO) and PHC (GoPOID) staff

Visit to hospital of NGO Partners in the districts

In service treatment facility

Meeting with NGO Partner teams

Disability aids for persons affected by leprosy

Confronting the microbial agent causes leprosy

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10. LIST OF ANNEXURES

Annex	Description
1	Terms of Reference for End Evaluation of POID AP Project (Abridged)
2	Details of respondents interviewed in the districts during End Evaluation
3	Success story – a prospect to value the human face of leprosy

Annexure 1

POID ANDHRA PRADESH PILOT PROJECT

TERMS OF REFERENCE (ToR) FOR END EVALUATION (Excerpts)

Rationale for the evaluation:

This project with a period of three years duration was launched in Sep. 2010 with support from FAIRMED-Bern. It is one of the significant projects of FAIRMED towards Disability Prevention & Medical Rehabilitation (DPMR) component of NLEP program through strengthening of Primary health care system. Through the end evaluation of the project, FAIRMED would draw lessons, document best practices and experiences and also understand the processes so as to replicate this model in other states / districts of the country.

Objectives (Evaluation questions):

1. Analyze and understand the extent to which the objectives of the project and their measures have been achieved (regarding logical framework in the Project document).
2. Document the key outcomes of the project implemented since September 2010 in Guntur & East Godavari districts of Andhra Pradesh.
3. Analyze the effectiveness (regarding the outcomes and not the cost effectiveness) of the strategies adopted (strengthen the Primary Health Care, strengthen self care in POID, increase access to POID among immobile and needy persons, enhance community mobilization and empowerment for POID)
   - *Process of formation of self help groups in both districts, it sustainability and appropriateness as a strategy for integration, manageability of this intervention at present time*
4. Identify synergies with the government departmental schemes that the project has facilitated, which has significantly contributed to the overall well-being of the affected communities, and what eventual other synergies could be utilized.
   - *Did this project influence policies and programmes of the government?*
5. Identify the role of key stakeholders that has contributed to the successful implementation and completion of the project.
6. Comment the Community Based Rehabilitation initiatives (relevance regarding the context, possible further development, community involvement)
   - *Are there some more opportunities in this kind of project to extend the interventions of rehabilitation to other disabilities or to develop further CBR approach?*
7. Assess the strengthening of the local health systems
   - *How to address the gap between what is supposed to be done by the different staff / professionals in the PHC and what is actually done (Refer report of Dr Krishnan: Year 2 end POID Evaluation, December 2012, pages 1-2)*
   - *What is the involvement of community in supportive actions to the leprosy affected persons?*
   - *Could we expect a higher added value through a higher level of participation of community (Handicap Society, Village Health Committees, others)*
   - *Does the involvement of ASHAs (detection, and Treatment completion) seem sustainable or are there some pre-conditions for these activities to be assured?*

8. Show the impact of the pilot in improving the quality of life of people affected with Leprosy (based on the main indicators and also through additional insights about quality of life)
9. Assess the strength and weaknesses of the Project Cycle Management
   - *How does the project organization (2 areas, 2 NGOs) function?*
   - *How does the project steering function (performance of the steering committee, knowledge sharing and the way to learn from the experiences)*
10. How reports of the Back-stopper have been used in order to adapt the interventions and plans of action? Show the sustainability of these interventions and the components of this project that could be replicated in another place.
    - *What is the level of integration and ownership by the health system of the POID interventions?*
    - *What are the keys in the sustainability of the present system in order to maintain the quality of case management at PHC level? Is this level of quality realistic in the outlook of integration?*
    - *What would be now the consequences of withdrawal of the support of FAIRMED and in what extent is it conceivable without jeopardizing the successes of the project so far? (For example: what is the future of the POID camps without the mobile teams: are the PHCs able to continue these activities by themselves?)*
11. Show lessons learnt and provide recommendations for a next phase of the project.
    - *What is/are the possible and appropriate option(s) for a phase II of this project: gradual phasing out, consolidation, replication in another district?*

Deliverables:

1. Submission of draft reports following desk review, field evaluation, data analysis including recommended strategies for POID project.
2. Submission of final report including the required clarifications and executive summary.
3. The findings of the evaluation may have to be disseminated in a suitable forum, the date and venue of which will be shared with the evaluator in advance. This would also include power point presentation, pictures etc.

Reporting:

The evaluator is expected to submit a draft report, which should have two sections, the first being the executive summary of the findings and the second being the detailed report of the evaluation findings inclusive of the data analysis and other observations. Inclusion of relevant photographs may be considered in the report. The drafts and final version of the report must be submitted to the Head Quarter of FAIRMED in Bern and to the FAIRMED office in Delhi.

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Annexure 2

POID AP PROJECT – END EVALUATION

DETAILS OF RESPONDENTS INTERVIEWED DURING FIELD VISITS IN PROJECT DISTRICTS

Date	District	Location	Name of respondent	Designation
09.12.2013	Hyderabad	DHS Office	Dr. Tarachand Naidu	State Leprosy Officer
09.12.2013	Hyderabad	DHS Office	Dr. P Michael Sukumar	State NLEP Consultant, LEPRA India
10.12.2013	Guntur	ADMHO	Dr (Mrs). P. Umadevi	ADM&HO (AIDS & Leprosy)
10.12.2013	Guntur	DRDA Office	Mr. G. S. Sunder Raj	Project Officer, CBR, DRDA
11.12.2013	Guntur	Amarthaluru PHC	Dr. A. Srinivasa Rao	Medical Officer
			Mr. Raghava Rao	Leprosy Physiotherapy Technician
			Mr. E. Srinivasa Rao	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
11.12.2013	Guntur	Mulpura PHC	Dr. S. Raju	Medical Officer
			Mr. T. Vijaya Raju	Deputy Para Medical Officer
			Mr. K. Vijaya	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
11.12.2013	Guntur	THW, TB Hospital	Focus Group Discussion with in-patients	
12.12.2013	Guntur	Peda Palakaluru PHC	Dr. K. Deepthi Kokila	Medical Officer
			Mr. V. Prasad	Assistant Para Medical Officer
			Mr. Mallikarjuna	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion

Date	District	Location	Name of respondent	Designation
12.12.2013	Guntur	Anandapeta UHC	Dr. Shabbeer	Medical Officer (NGO)
			Mr. T. Ashok Kumar	Assistant Para Medical Officer
12.12.2013	Guntur	ADM&HO Office	Dr. Kameshwar Prasad	Sample Survey Assessment Unit
13.12.2013	Guntur	Nadurupadu PHC	Dr. Rajesh	Medical Officer
			Mr. K. A. Rambabu	Deputy Para Medical Officer
			Mr. Chandrasekar	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
13.12.2013	Guntur	Kottapakonda PHC	Dr. Hanuma Kumar	Medical Officer
			Mr. Srinivas	Assistant Para Medical Officer
			Mr. D. Ramaiah	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
14.12.2013	Guntur	Tadikonda PHC	Dr. Sravanthi	Medical Officer
			Mr. Papa Rao	Assistant Para Medical Officer
			Mr. R. Nageswara Rao	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
14.12.2013	Guntur	Emani village	Self Help Group	Venkateswara Podupu Group
14.12.2013	Guntur	Gretnaltes, Morampudi	Mr. Hemachandu	Project Director & Project team
15.12.2013	East Godavari	RISDT, Kathipudi	Mr. N. Slesser Babu	Project Director & Project team
16.12.2013	East Godavari	Kakinada	Dr. M. Pavan Kumar	ADM&HO (AIDS & Leprosy)
16.12.2013	East Godavari	Kakinada	Mr. G. Chandrasekhar Raju	Project Director, DRDA
16.12.2013	East Godavari	THW, Kakinada	Dr. M. Ravi	Medical Officer & staff nurses

Date	District	Location	Name of respondent	Designation
17.12.2013	East Godavari	Kirlampudi PHC	Dr. B. Chandra Kiran Babu	Medical Officer
			Mr. N. Sanjeeva Reddy	Deputy Para Medical Officer
			Mr. B. Yerrabbai	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
17.12.2013	East Godavari	Pulimeru PHC	Dr. K. Nageswara Rao	Medical Officer
			Mr. M. Ramakrishna	Deputy Para Medical Officer
			Mr. V. Kameswara Rao	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
17.12.2013	East Godavari	Jaggampeta PHC	Dr. G.S. Charles	Medical Officer
			Mrs. K. Veeralakshmi	Deputy Para Medical Officer
			Mr. K. Rammohan Rao	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
18.12.2013	East Godavari	Biccavolu PHC	Dr. Y. Anantha Kumar	Medical Officer
			Mr. K. Srinivasa Rao	Assistant Para Medical Officer
			Mr. G. Kamal Seshu	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
18.12.2013	East Godavari	Machavaram PHC	Dr. K. Sivaranjini	Medical Officer
			Mr. N.V. Radhakrshna	Deputy Para Medical Officer
			Mr. S. Mallikarjuna Rao	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
18.12.2013	East Godavari	Rayavaram PHC	Dr. P. Ganga Bhavani	Medical Officer
			Mr. P. Venkateswara Rao	Assistant Para Medical Officer
			Mr. K. Bapiraju	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion

Date	District	Location	Name of respondent	Designation
19.12.2013	East Godavari	Sitaramapuram UHC	Dr. P. Prabhakara rao	Medical Officer
			Mr. K. Prasada Rao	Assistant Para Medical Officer
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
19.12.2013	East Godavari	Jyothi Nagar Leprosy Colony	Mr. M. Krishna Murthi	Deputy Para Medical Officer
19.12.2013	East Godavari	U. Kothapalli PHC	Dr. R. Srinivas Naik	Medical Officer
			Mr. LVVS. Srinivas	Assistant Para Medical Officer
			Mr. S. V. Rama Reddy	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion
19.12.2013	East Godavari	K. Perumallapuram PHC	Dr. P. Ravikumar	Medical Officer
			Mr. K. Prasad	Deputy Para Medical Officer
			Mr. M. Eliya	Govt. Officer - POID
			ASHAs	Focused Group Discussion
			PALs	Focused Group Discussion

DETAILS OF RESPONDENTS INTERVIEWED DURING FIELD VISITS IN WEST GODAVARI DISTRICT (CONTROL)

Date	District	Location	Name of respondent	Designation
20.12.2013	West Godavari	Dommeru PHC	Mr. V. Kiran Kumar	Deputy Para Medical Officer
20.12.2013	West Godavari	Chagallu PHC	Mr. J. Veerraju	Assistant Para Medical Officer
20.12.2013	West Godavari	Tadimalla PHC	Dr. Nadiya	Medical Officer
			Mr. Elisha	Deputy Para Medical Officer

Annexure 3

SUCCESS STORY – A PROSPECT TO VALUE THE HUMAN FACE OF LEPROSY

Gurrala Rajamani, 34 years female, married; having two young daughters and her husband is working as an agent for Life Insurance Corporation of India. Rajamani is one of the two children to her parents and come from a poor family, residing in Nagulapalli village in East Godavari district of Andhra Pradesh. Her father, Mr. Gurrala Venkata Rao is an agricultural labour and her mother is a housewife. He was a sufferer of leprosy and got cured with the modern treatment (MDT) but left with residual disability on the foot. While she was young, she had seen the plight of her father who had difficulty in working in the field due to non-healing wound on his foot due to leprosy.

Although he did not face any discrimination by his family, he had to embrace the wrath of social stigma in the local community because of the foul smell from his sole wounds. Yet, he braved his life and supported the education of both children even with his meager earnings. She used to nurse the wounds of her father regularly and finally decided to become a qualified nurse, so that she can serve the people who are suffering from leprosy.

After her schooling, Rajamani completed her General Nurse and Midwife (GNM) training at Sri Venkateswara School of Nursing, Mulkajgiri, Hyderabad in 2004 and secured a job with public Health Department, Government of Andhra Pradesh in 2009. Currently she is working as a public health nurse in Kotha Perumallapuram PHC since 3 years in East Godavari district of Andhra Pradesh.

Sister Rajamani nursing the wounds of persons affected by leprosy at Kotha Perumallapuram PHC

Incidentally, the POID camps organized by RISDT, a NGO partner in Kotha Perumallapuram PHC of East Godavari district gave **an opportunity to fulfill her heart's desire as a tribute to her ailing father due to leprosy.** During the POID camps, **she used to dress the wounds of persons affected by leprosy and also teach them on the self care** measures. She offers them snacks **and shares her love and passion as her own family members.** Besides, she gives training to her colleagues on leprosy at PHC including ANMs and ASHAs during the leisure time and motivates them to serve the people affected by leprosy.

Observing her dedication and determination to bring smile on the face of persons affected by leprosy, she was conferred with **Best Service Award by the Government of Andhra Pradesh** and also received an **Appreciation certificate** from **Mrs. Neethu Kumari Prasad,** the **District Collector of East Godavari on the eve of Republic Day** on 26 January 2013. Now, she has become a role model and an inspiration to several health workers working in the public health system that has brought dignity and equity for the persons affected by leprosy as a matter of right.

Sis. Rajamani with her father Mr.Venkata Rao

Receiving certificate from District Collector