

Swiss Emmaus India

End of Evaluation of CDLCP Project: GRETNALTES

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1 BACKGROUND

1.1 INTRODUCTION

Swiss Emmaus India, long term NLEP partners at the National level and operating in four states (Andhra Pradesh, Karnataka, Tamil Nadu, and Maharashtra), has consistently provided five-decade support to the National Leprosy Elimination Program (NLEP) through its projects, institutions, and partner organizations. As a founding members of International Federation of Anti Leprosy Associations (ILEP), its' collaboration with the Central Leprosy Division (CLD) of the Ministry of Health and Family Welfare, Government of India has made a mark in the provision of primary, secondary and tertiary care to the people affected by leprosy. In the State of Andhra Pradesh, it operates in three districts through NGO partners, namely, East Godavari (RISDT, Rural India Self Development Trust), Guntur (GRETANALES, Greater Tenali Leprosy Treatment and Education Scheme Society) and Chittoor (ESRHLP, Emmaus Swiss Referral Hospital & Leprosy Project) districts. The services it provides include primary care, tertiary care and community based services to people affected by leprosy and their families.

1.2 THE PROJECT

The Comprehensive District Leprosy Control Project (CDLCP, 2014-2017), a continuation of its POID (Prevention of Impairment & Disability; 2010 to 2013), has set the goal to improve the quality of life of the leprosy affected persons by strengthening the existing public health care delivery system for detection of new cases of leprosy as well as reaction and neuritis cases early enough before development of any deformity, generating community level participation and strengthening home-based care for rationalization of the tertiary care, provisioning of best practice tertiary care in the referral hospital, providing technical support in terms of capacity building and monitoring for the program and innovating the interventions by introducing android based data generation from the field

The project objective is to strengthening POID services at the primary health care system, referral hospital level (OBA) and community level. It intended to undertake operation research in in key areas of leprosy within the project to strengthen policy decisions and to develop project management system for effective implementation of the project. The project implemented through two NGOs (RISDT at East Godavari and GRETANALTES at Guntur) and the State/District Leprosy Society, Department of Health and Family Welfare, Government of Andhra Pradesh. The project will provide special attention to following target groups: new cases diagnosed without deformity, old treated cases without deformity, old treated and new cases with grade 1 deformity, old treated and new cases with grade 2 deformity and people affected by leprosy who are eligible for RCS (Re-constructive Surgery).

2 INTERVENTION THEORY OF CHANGE

Inputs	Outputs	Outcomes	Impact
<p>Financial and Manpower Resources for the implementation A POID strategy within General Health System, at the referral hospital, and at the community level Support for operational research as needed</p>	<p>Strategy 1: Strengthen existing public health care delivery system for detection of new cases of leprosy as well as reaction and neuritis cases before development of any deformity:</p> <ol style="list-style-type: none"> 1. To improve the POID services in primary health care <ol style="list-style-type: none"> 1.1. Strengthening the capacity of the NEP Coordinator at PHC level <ol style="list-style-type: none"> 1.1.1. Refresher training of the identified NLEP staff at PHC level 1.2. Adopt measures to detect the hidden cases in the community <ol style="list-style-type: none"> 1.2.1. Identification and examination of the contacts of the newly diagnosed cases & follow-up of all such cases. 1.2.2. Special search activities in low / high endemic blocks (mandals). 1.2.3. Ensure systematic school health examination 1.3. Improve involvement of private sector & Medical colleges <ol style="list-style-type: none"> 1.3.1. Identify private practitioners / skin Department in Medical colleges providing leprosy services in the district. <ol style="list-style-type: none"> 1.3.1.1.1. Promote them for reporting of the cases provided treatment through them. 1.4. Improve early detection of Nerve Function Impairment cases and their management 	<p>People with leprosy are prevented from developing disability and impairment</p> <ol style="list-style-type: none"> 1.1. Annual new case detection rate (ANCDR) of the district increases 1.2: Increase in no. of cases managed for reaction / neuritis by PHCs / district. 1.3: Disability grade 0 cases among the new cases remain on grade 0 1.4: Disability Grade I among the new cases remain on grade I or improve to grade 0 1.5: Reduction in Grade-II disability cases among the new cases)) 	<p>Overall goal: Improved quality of life of the leprosy affected persons</p>

	<p>1.4.1. Refresher training of the PHC Medical Officers with special emphasis on Nerve function assessment.</p> <p>1.4.2. Nerve Function Assessment for all the newly diagnosed cases every month and initiation of Steroid therapy for all the cases of recent development.</p> <p>1.4.3. To follow the high risk (MB) cases even after RFT (Release from treatment) for at least 3 years for early detection of reaction /neuritis.</p> <p>1.4.4. Ensure availability of Prednisolone and Clofazimine at all the PHCs.</p>	
	<p>1.5. All the disabled persons due to leprosy get the required care / support</p>	
	<p>1.5.1. Baseline details of all the old and new cases (under treatment) are captured using the line list.</p> <p>1.5.2. List of disabled patients (ulcers, deformity, and cataract) obtained after screening.</p> <p>1.5.3. Management of simple ulcer cases provided at PHC level and others referred for further management at referral hospital.</p> <p>1.5.4. Eligible patients are provided the due disability benefits from / outside the program.</p>	
	<p>2. To provide POID services at referral hospital level</p>	
	<p>2.1. Provision of specialized services for management of complicated cases in the referral hospital (OBA).</p> <p>2.2. Strengthening OBA, recording and reporting of the hospital</p>	

	and field activities	
	3. To strengthen POID services at community level	
	3.1. Improve involvement of ASHAs in case detection	
	3.1.1. Review the performance of ASHAs in the PHC level monthly meetings with respect to suspect referral and treatment completion.	
	3.1.2. Ensure payment of incentives to ASHAs for diagnosis and treatment completion.	
	3.1.3. Improve involvement of grass-root level health workers in management of ulcers at community level	
	3.2. Improve involvement of grass-root level health workers in management of ulcers at community level.	
	3.2.1. Train ANMs / ASHAs on "Self-care practices for Leprosy affected persons" and in providing home based care for the ulcer cases under supervision. (PHC & NGO staff)	
	3.2.2. Ensure availability of required material for ulcer care from the PHC (NRHM) fund.	
	4. To develop project management system for effective implementation of the project	
	4.1. Deployment of trained manpower for project management	
	4.1.1. To appoint a Project Manager for the Project monitoring and supervision	
	4.2. Recording and reporting of the hospital and field activities	

	<p>4.2.1.To develop monthly reporting system capturing the activities with the Project proposal and YPO.</p>	
	<p>4.3. Improvement of the monitoring system of the Primary health care system</p>	
	<p>4.3.1.To strengthen monthly meetings at district level through evidence based analytical presentations.</p> <p>4.3.2. To have backstopping through an external consultant at periodic intervals</p>	
	<p>5. To identify and undertake operation research in key areas of leprosy within the project to strengthen policy decisions.</p>	

2.1 THE EVALUATION

The project is completing four years of successful implementation and is at the end of the project cycle. Swiss Emmaus India intends to evaluate the project and appointed two consultants Dr. Anita Rego and Dr. Kamaraj. The purpose of this evaluation is to assess the extent to which the project has been able to fulfil the set objectives as reflected in the original proposal. Specifically, it explored on the (1) the level of change brought about by the activities of the project among the relevant stakeholders and the community as a whole in regards to supporting the POID services for people affected by leprosy in the community (2) assessing the management capacity of the implementing agency, capacity of the staffs deployed from the collaborating agencies including Swiss Emmaus India in delivering their roles and responsibilities in relation to the project output. It will identify the achievements, challenges, lessons learnt and effective practices of the project. Lastly, taking into account the stated goals and objectives of the project, and its objectives, the evaluator will assess the adequacy of the logical framework, its indicators and logical hierarchy of output-outcome-impact levels.

2.1.1 Methodology and approach

The evaluation is conducted by two consultants – one focusing on program activities in the field and the other on the project management. The evaluation was conducted in the month of June and the analysis reports developed in the month of July. One of the evaluators considered the technical aspects of the evaluation and hence reviewed the Primary Health Care system, the NGO Referral Centre and the Private Health Service providers. The second evaluator considered the program management component and hence considered the Community component. The two

consultants continuously engaged with each other and ensured that the findings were triangulated and finalised.

The evaluation used mixed methods for data collection. An initial desk review of the different project documents was carried out. The documents were provided well in advance by FAIRMED.

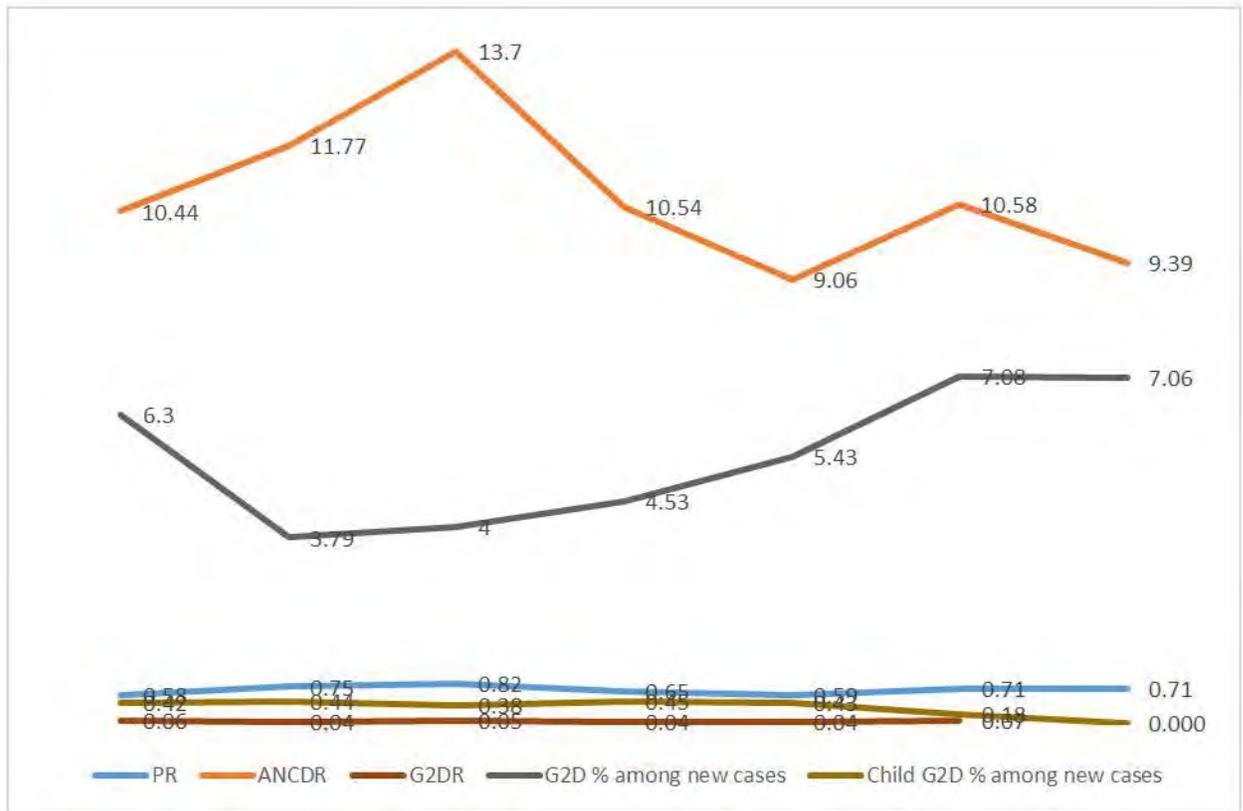
3 LEARNING FROM THE PROJECT

3.1 STRENGTHEN EXISTING PUBLIC HEALTH CARE DELIVERY SYSTEM FOR DETECTION OF NEW CASES OF LEPROSY AS WELL AS REACTION AND NEURITIS CASES BEFORE DEVELOPMENT OF ANY DEFORMITY:

3.1.1 Trends of Leprosy over the years at Guntur

Table: Trend in NLEP Indicators

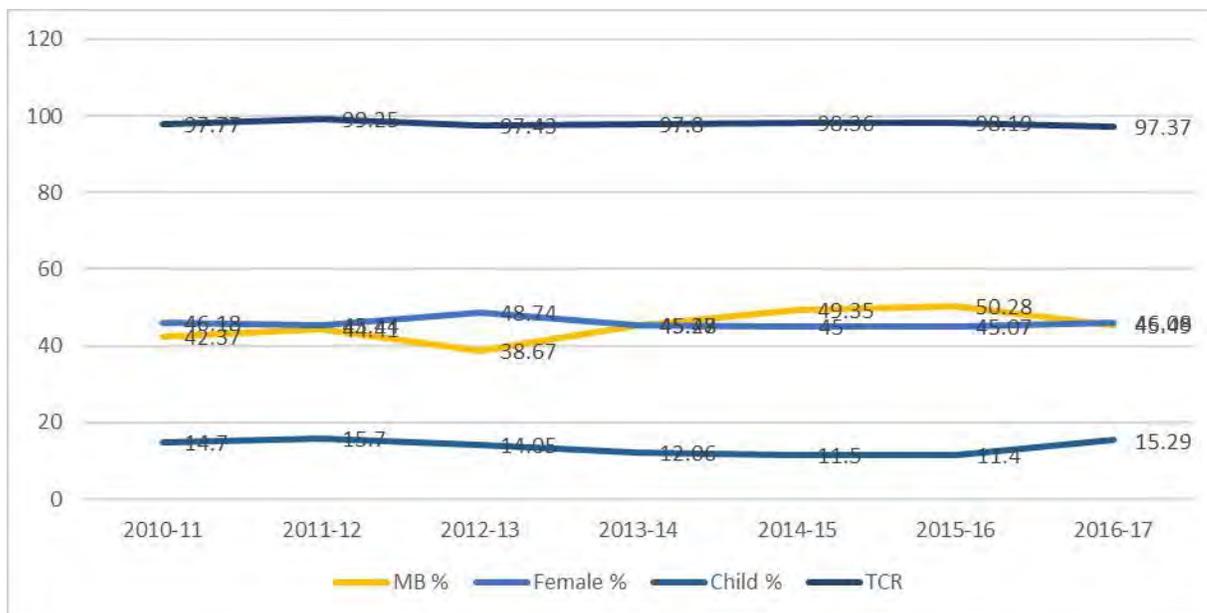
Guntur	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17
PR	0.58	0.75	0.82	0.65	0.59	0.71	0.71
ANCDR	10.44	11.77	13.7	10.54	9.06	10.58	9.39
MB %	42.37	44.41	38.67	45.28	49.35	50.28	45.49
Female %	46.18	45.44	48.74	45.47	45	45.07	46.08
Child %	14.7	15.7	14.05	12.06	11.5	11.4	15.29
G2DR	0.06	0.04	0.05	0.04	0.04	0.07	
G2D % among new cases	6.3	3.79	4	4.53	5.43	7.08	7.06
Child G2D % among new cases	0.42	0.44	0.38	0.45	0.43	0.18	0.00
TCR	97.77	99.25	97.43	97.8	98.36	98.19	97.37



The prevalence rate of Guntur district has reached a plateau well below the elimination target of 1 new case for every 10,000 population. This rate has shown an increasing trend in the last two years a year after the inception of CDLCP Guntur. The support to intensified case detection activities through leprosy campaigns and focal survey in “zero PR” areas are resulting in increased detection of new cases including the hidden cases of the previous years. The ongoing trend calls for sustained support to case detection activities in the district with systematic case validation.

Similarly, the ANCDR records a drastic fall since 2012-13 due to various reasons, which the project has helped to streamline since 2014.

Grade 2 Disability (Rate & Proportion) follows the same pattern. Following the sudden increase, a year after project onset, the disability among new cases is still at the new high, which again points to sustaining efforts to reduce the incidence of disability in new cases. The fall in child cases with disability is a positive sign attributed by CDLCP’s support to school health programmes. The ‘zero child case with disability’ that was achieved last year should be sustained in the coming years.



MB proportion among new cases like other indicators has shown an increase for two years and a gradual fall last year. Early case detection should be continued with corresponding increase in PB proportion. However, it is to be noted that increasing MB proportion among males and older age groups would suggest that the disease is in the declining stages of endemicity. This data is not available for analysis.

The female proportion has reached a plateau over the years accounting for nearly 50% of the new cases. The child proportion has shown an increase in the last year with more child cases are being detected through organized efforts. A high child proportion may be a sign of active and recent transmission of the disease. Nevertheless, it could be due to active detection through school surveys, and increased detection of 'self-healing' cases.

Treatment Completion Rate is above 95% and has reached a plateau above that level. There is a marginal decrease during the last year which may not be statistically significant. Migration of new cases in the newly divided state with reallocation of mandals and divisions were the reasons stated by ASHAs and ANMs for not achieving 100% treatment completion rate.

3.1.2 Situation of Human Resources at the General Health system

3.1.2.1 Medical Officer/MO at Primary Health Centre/PHC

Seven PHCs, one CHC (recently upgraded) and 2 Urban Health Centres/UHC were visited in the second phase of the evaluation. All PHC and UHC that were visited have a Medical Officer in place. In G. Mupalla PHC, the MO was not available during the visit, as she had gone out for a diarrhoeal outbreak investigation. The Thuphan Nagar MO of UHC was not available.

MOs at 7 of 8 PHC are young, committed, and willing to learn new skills. The CHC MO is a senior dermatologist. The UHC MOs are senior, retired doctors from the general health care system.

Duration of posting in the same PHC ranges between 1 to 5 years. The UHC MOs were posted for about 3 to 5 months.

MOs (8 of 10) have a good basic knowledge in leprosy. One is a CHC dermatologist. They are capable of diagnosing suspects referred by ASHA/ANM. MOs are confident with easy cases (simple, anaesthetic patch), but the difficult ones are referred to Guntur Government Hospital or district for confirmation of diagnosis. In most cases, MOs are supported by/dependant on the APMO/DPMO for case confirmation.

Except CHC MO who is a dermatologist, all other MOs have basic knowledge in Reaction & Neuritis but are not confident of diagnosing and managing R&N.

3.1.2.2 Deputy/Assistant Para Medical Officer (D/APMO)

APMOs were present in 3 out of 8 PHCs visited. One APMO is managing two UHCs. APMOs are not replaced following their retirement from service. Instead, a nodal person for leprosy activities is identified within the staff roll and are given basic training (on-job) for record maintenance, reporting and to contact the DPMO. This is given as an additional responsibility and there are no salary allowances given for this additional activity. Field staff with a supervisory role at the PHC is chosen for this purpose. In most PHCs, Multi-Purpose Health Supervisor/Assistant (MPHS/A) is given this additional role.

DPMOs are based in a PHC but are responsible for 5 to 8 PHCs in their division. Currently, there are 2 to 3 DPMOs in a division. Their number is also reducing, as they are not replaced after their retirement. Once a week, they are stationed in a PHC, and on other days, they visit/supervise other PHCs allocated to them based on their advance tour programme (ATP) approved by the Para Medical Officer/PMO at the district level. APMOs (where available) report to the DPMO.

Two APMOs and 4 DPMOs were available during visits to PHC, UHC, and the Medical College. Others were not available as they had gone on visits in preparation for the monthly meeting.

Description	2014 (Jan - Dec)	2015 (Jan - Dec)	2016 (Jan - Dec)	2017 (Jan - June)
* Increase in no. of cases managed for reaction / neuritis by PHCs / district	18/530	42/501	38/456	19/301
*Disability grade 0 cases among the new cases remain on grade 0	489/530	462/501	411/456	275/301
*Disability Grade I among the new cases remain on grade I or improve to grade 0	4/530	6/501	5/456	6/301
*Reduction in Grade-II disability cases among the new cases	2/37	4/33	3/40	1/20

3.1.3 Case on treatment

All PHC and UHCs have cases on treatment. Health facility wise cases on hold was available from 3 PHCs – 2 PB & 1 MB. Yedlapalli PHC of Tenali division has 'zero' cases for two consecutive years,

hence has been classified as 'zero PR PHC.' In this regard, a training session was organized by the DLO office for all field staff in the PHC for a complete door-to-door survey of the PHC area.

3.1.4 Reaction & Neuritis (R&N)

No R&N cases currently on treatment. 3 MOs of PHC said they can diagnose R&N. Others, except the dermatologist in CHC refer the case to Guntur Government Hospital or to DNT Consultant. During the visit, there was one case on Reaction but the MO could not diagnose it. The MO said she was not confident to diagnose R&N, and would refer such cases to Guntur Hospital. Referral slips are sent through the patient and are followed up by the DPMO/APMO/DC. Prednisolones are available in all PHC and are given from general stock and are not supplied as part of leprosy drugs and supplies. Clofazimine is not available at the PHC; we were made to understand that the stocks are placed at the district hospital.

3.1.5 Case Validation and Contact Tracing

All new cases are validated within a month of diagnosis by the DPMO accompanied by the Divisional Coordinator/DC of the CDLCP project. This is done during the home visits at the community level. Date of validation is not mentioned in the patient chart. Contact survey followed by contract tracing of immediate household/family is also done at the same time with the help of ASHA/ANM (for female contacts) and recorded in the patient chart (sometimes in the survey register as well). It was told that re-examination of contacts is also being done at the end of treatment but this could not be verified as it is not being documented in the patient chart or elsewhere. A patient chart in Karalapadu PHC was incomplete with no signature of the Medical Officer on it.

3.1.6 Nerve Function Assessment/NFA

NFA at the start of treatment was done on all new patients, and was recorded in the patient chart. The follow-up repeat assessment at 3 months' interval for those on MDT, and every 2 weeks for those on steroids are not being followed.

Skills of two APMOs and four DPMOs in doing sensory and voluntary motor testing were 'not satisfactory'. The capacity of the divisional coordinator in NFA is not very different - either the same or slightly better than the DPMO/APMO. The nodal person could not do NFA as they were not trained.

3.1.7 New case with Grade 2 Disability/G2D

Each of the four PHC/UHCs visited reported one new case with G2D. Three patients with G2D were interviewed. One of them who was a cook said that he was not aware that his patch could have been due to leprosy, and had lost time to seek treatment until anaesthesia in his hands has set in. The concerned ASHA/ANM said that he was from the neighbouring PHC! His disability could have been prevented through public awareness and early screening by ASHA/ANM. The second patient with leprosy disability had migrated from Ongole recently, and was never on treatment earlier. He is currently on treatment in Vemuru PHC of Tenali division. The third person currently staying with his relatives in Guntur city/town belongs to Thuphan Nagar UHC. He was diagnosed 5 years back in his hometown but he refused to believe it was leprosy, and did not take treatment until it was late.

A young teenage boy who had presented with a patch but dropped out of treatment had presented with Grade 2 deformity on the day of our visit in one of the PHC. The boy had a family member with leprosy. The boy had completed high school education and was living in the neighbourhood of the ASHA, yet, the NLEP teams' efforts to motivate him had failed and only when he developed G2D, he sought help.

3.1.8 Deformity Register

Overall, 59 patients were registered in 4 of 10 PHC/UHC visited. The registers were not available for verification in other PHC as the DPMO/APMO were away for a meeting. But, it was told that the registers were up-to-date. Since there was no column for date, the last entry could not be verified.

Division and PHC-wise list of leprosy patients with disability as available with the project staff captured through tablets is not tallying with that of deformity register with DPMO. This discrepancy/differences should be reconciled, and a common/uniform list will help in planning and service delivery in an efficient and effective way.

3.1.9 Self-Care Kit and Splints

The project has been able to make a clear shift from the direct provision of self-care kits through the project to accessing the supplies provided by the Government. Self-Care Kit (readymade) and splints are not purchased by the state/district NLEP. Dressing materials are given to ulcer patients at the PHCs and the sub-centers from the central pool of drugs. However, the knowledge that self-care supplies are available at the Sub-Centre was not widely known among the people. The people with leprosy are provided food supplies for enhancing nutritional status by another NGO in the area supplied at the PHC and hence people collect their self-care supplies along with their food supplies during their monthly visit to the PHC. This strategy may bring people to the PHC on a monthly basis, however, unless the people are aware and link themselves to the Sub-Centre for self-care supplies, there is a risk in delayed care of the ulcer if they wait until their monthly visit to seek self-care supplies and treatment.

3.1.10 Strengthening POID at the General Health system

People we visited at the PHC and met during community interactions have been seeking help from the PHC as a first step for treatment of ulcers; the link with the PHC is established with the linkage with the monthly ration supply as explained earlier. What is also noted is that around 60 to 70% of the people met had received RCS services from GRETANALES. What is noted alongside is the lower focus on exercises as part of self-care.

People approached the PHC directly or get linked to the PHC through the ASHA. In every PHC visited, the ANMs provided treatment for the ulcers at the PHC and also taught people on how to take care of the ulcers. It is observed that this group of staff members have no apprehension (stigma or discrimination) in touching/dressing ulcer. It is only at one of the PHC where none of the ANMs and ASHA had witnessed a person with leprosy in their workspace; there were apprehension to use the same seating where the people with leprosy had used. While this PHC had several people with leprosy, the ANM and ASHA who were from the villages from where the people with leprosy hailed from could not be met; these people were not in touch with the ASHA and ANMs on a regular basis.

The project team has trained PHC staff on self-care however, the internalisation process and practice of self-care among people is seen to be low. While the project has promoted self-care, the need to reinforce the practice of self-care is also not on the top of the mind among PHC or project staff members; the same trends are seen in the people affected by leprosy. One of the dipstick assessment to check on the practice of self-care among people that was carried out is to check on the feet and hands of the people whom we interviewed. Our observation is that 60-70% was not regular on self-care. The PHCs had initiated the concept of group self-care at the centre. Self-care could not be sustained as a routine activity and very few (four members) had witnessed them during their PHC visits. Similarly, group self-care was promoted in the communities where a few people could motivate each other to do self-care and also discuss issues of concern. We were able to see two such groups at the villages, what can be said is that these meetings appeared to be sporadic and took a lot of effort given that people do not stay within the same geographies. Most of the people are at work and making time and energy for such meeting is good but was difficult to implement.

Taking into consideration the lowered attention to self-care and active ulcers in the group we met, it can be suggested that the General Health System can focus more on promoting self-care in a way that is effective and efficient for ulcer prevention and healing of ulcers. This can be undertaken as a worthwhile programmatic or intervention for enhancing effectiveness of POID intervention. Additionally, the disability register at the PHC level should be updated regularly and checked for completion every 6 months to have the list of all disabilities due to leprosy and the services required.

1.1. Ulcer Care, referral for ulcer care and Reconstructive Surgery)

In leprosy/POID programme, 'ulcer care' is a major component and a major burden to the health care system which is often neglected by the PHC staff. The POID projects focuses on prevention and treatment of ulcer care through self-care strategy, treatment of ulcers through the primary health care system, and ensuring prompt referrals. The treatment of ulcers is carried out by the person or by the PHC staff at the PHC or at the sub-centre

Moreover, it was also observed that the available ANM including Male Nursing Orderly/MNO in some PHC show positive attitude in dressing leprosy ulcers but with limited knowledge & skills and resources. Use of gauze over cotton for dressing, MSGA over Povidone Iodine ointment, callous removal, draining sinus and deep dressing are part of ulcer dressing in leprosy. PHCs do not have soaking tub, scalpel handle and blade, gauze bandage, MSGA, stool/chair, leg rest, dressing area etc.

Most people we met and interviewed expressed fair healing of ulcer and it was corroborated with our observation. We met several persons with active ulcers. Almost all persons, who had ulcers, had sought help from GRETANALES and those treated were followed at the PHC during ulcer remission. Among the 23 people we met 'without ulcers', their last ulcer was two to three years back. This is noteworthy and encouraging trend. It can be affirmatively said that the successful reduction is contributed to the POID intervention, however, it may be premature to attribute it only to the intervention inputs given the multiple forces that are working in the space.

3.1.11 Protective Footwear/MCR

Annually, foot outline of patients requiring MCR are collected at the PHC level by the DPMO/APMO/MPHS/HA and are given to the DLO office. DLO office places an order to GRETNALTES to manufacture and supply. The final product with patient/PHC identity is given to DLO office, which delivers it to the DPMO during the monthly meeting/visits who in turn passes it on to the APMO/nodal person at the PHC. The patients are then informed to come and collect it from the PHC.

Overall, 40 patients were given MCR in 9 of 10 PHC/UHCs last year. In Karalapadu PHC, no patients require MCR footwear, as there are no anaesthetic feet or ulcer in their record. The Katuri Medical College refers their patients requiring MCR to a nearby private source. The 'unmet need' in MCR supply to needy (anaesthetic feet) leprosy patients in Guntur is about 5%. It was told that the DLO procures MCR footwear from sources other than GRETNALTES, Morampudi. What needs to be noted here is that the people received only once in a year, a supply side shortage that can put several affected persons at risk for ulcers.

We used a dipstick assessment of counting those who wore MCR on the day of the interview as an indicator to understand the regular usage. The use of MCR footwear among people provided with a MCR pair through the government supplies is very low, at around 30% (13 of 42 those needing MCR had worn the MCR on the day of the interview). Those who are wearing them do so fairly regularly. However, those who do not use them provide varied reasons for not using them; the most common complaint was that they are heavy to use, there were concerns on the strap, it is not comfortable and so on. The other reason was there were problems with sizes provided. We discussed with the MCR manufactures, GRETNALTES (one of the manufacturers) on the same and checked on the footwear. The MCR was robust, looked good and had a rubber tyre sole. The rubber sole base to ensure that the feet are well protected ensuring that sharp objects do not get into the soles. What could be said is that there is a need to balance quality with comfort for the consumers.

The people we interviewed expressed that they were not getting appropriate size MCR. In one occasion, the person had got one size smaller and he was holding on to it for six months without using the same. What is told by the NGO is that they do not get footprints and they are given only sizes that need to be made. There are concerns on the indenting and the distribution process that need to be studied to put in place a robust system in place. There is a window of opportunity for the PHC staff and the NGO to further promote and increase the use of MCR given the poor utilisation of MCR.

2. GENERATING COMMUNITY LEVEL PARTICIPATION AND STRENGTHENING HOME-BASED CARE FOR RATIONALIZATION OF THE TERTIARY CARE

2.1. Systematised approach for screening of suspects and review of old cases at community

Description	2014 (Jan - Dec)	2015 (Jan- Dec)	2016 (Jan - Dec)	2017 (Jan - June)

No.& % of new leprosy cases reported by ASHAs	279 - 53%	288 - 57%	305 - 67%	209 - 69%
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With the support of the project, the government system through the General Health System has institutionalised a community approach for screening leprosy suspect in the community and for review of old cases in the community. Every first Thursday of the month is designated as leprosy day across the State and the trained ASHA carries out case detection screening through a door to door survey in her demarcated geographic area. The focus is on identifying people with patches and carrying out a preliminary assessment for absence of sensation and associated conditions such as loss of hair on the patch. The screening of suspects and review of old cases is preceded by ASHA day, held every first Tuesday of the month. During the ASHA day, the Medical Officer/ APMO/ DPMO takes a session on the leprosy for the ASHAs. The Government provides incentives to the ASHA for early detection and treatment, Rs. 250 for a confirmed leprosy case detection without disabilities and Rs. 200 with disabilities, Rs. 400 for PB case wherein the duration of treatment is 6 months and Rs. 600 for MB case treatment. In addition, special campaigns such as LCDC have been conducted by the District Leprosy Unit to identify hidden cases in the community in addition to the routine screening wherein the NGO was an active partner to the campaign. In the district, there is a dependence on campaign as a strategy for identifying suspects. Screening is carried out on a monthly basis; however, it is done only for select number of houses (60 houses) in a given month.

Through the CDLCP project, GRETANALES is supporting the general health system in reducing disabilities through early detection well before the onset of disabilities or deformities. The trained ASHA is encouraged to detect cases through two processes: (i) monthly screening (ii) contacts during the month. What is noted is that ASHA have been visiting the households as part of survey as well as through door to door contacts. Each month she has been able to refer 1 or 2 persons who have skin pigmentation to the PHC for confirmation of leprosy every month.

The interactions with the ASHA, the people and a Gram Panchayat leader reflected that the survey and community outreach through the ASHA is being carried out in the villages visited and in the areas of the ASHA met. The ASHA takes the signature on the survey register from the Gram Panchayat Leader and notes the data on the survey template. The confirmed cases are noted in the new case register specifying the level of disability by the PHC staff when the case is confirmed. What is to be noted is that the ASHA covers about 60 households during the survey in a month and would require 4 to 5 months to complete survey of all households. This is also confirmed by the NLEP staff members we met. In one of the PHC, we observed that the system had considered referrals made by the ASHA as walk-in. This can be demoralising for an ASHA who had motivated suspects and sent them for the confirmatory test to the PHC.

The discussion on leprosy on ASHA Day held on first Tuesday of each month at each of the PHC ensures that the agenda of leprosy is on the top of the minds of the ASHA. The input from the Medical Officer or the Nodal person refreshes their knowledge and clarifies any doubts that they have in the field. Annually, the project staff members of GRETANALES carry out one-day session at the PHC. The leprosy day is designated as the first Thursday where the ASHA is expected to carry out the monthly leprosy survey at each of the villages.

What is inferred from our interactions with the ASHA is that the identifying 'people having anaesthesia' especially in the hands, feet and elbow is not top of the minds of the ASHA. This corroborates with the very low referrals of people with only anaesthesia. It is only during the field visits of the ANM when she actively engages to ask specific probes for persons with anaesthesia that they are identified. In our discussions with the team, probing for people with anaesthesia was also not on the top of the mind of the ANM.

Simple signs for identification of suspects are also known to the community leaders and reportedly, they report that have been proactively informing people. While such referrals cannot be tracked, it is an indicator that community messaging is being carried out and these leaders are aware of the importance of connecting those people with patches to the PHC/ASHA.

The District Leprosy Unit has promoted two new campaigns for early identification and for hidden case detection: leprosy case detection drive (LCDC) and the SPARSH IEC campaign with the intention of early detection and treatment. As part of LCDC campaign, in high endemic districts the ASHA and a male volunteer detected most of the new cases at the community level through house to house visits based on a micro-plan. Prior to the roll out, meetings were conducted in the community with community leaders and intense IEC activities were conducted to inform the community. The feedback was promptly provided with an immediate analysis and followed by treatment and corrective action. The overall response was good and the data shows that the campaign resulted in identify double to three times the number of cases in some pockets during the campaign. The "Sparsh Leprosy Awareness Campaign (SLAC)" on the occasion of Anti-Leprosy Day, promoted community participation in diagnosis and treatment of leprosy in its early stages. It also generated awareness about the disease to help in early diagnosis and treatment. It seeks to promote decentralised community-based demand-driven approach from present centralised top-down delivery-driven approach to fight the disease. It also empowered local communities to take over the responsibility of sensitising people to not stigmatise and discriminate against those affected. The onus it put on people helped in increasing awareness and was a step towards destigmatising leprosy.

In areas where new cases are identified, a contact survey is conducted. In the neighbourhood of the household (surrounding 10 metres), all members are examined. For those suspects, smear examination is carried out and those diagnosed are put under MDT. This is clearly understood and reported.

The suspects identified by the ASHA at the field or during campaigns or as direct walk-ins are referred to the PHC for further evaluation and confirmation. While the date is not fixed as leprosy evaluation day, most often than not, the suspects approach the PHC in the subsequent two or three days. The Medical Officer initiates the treatment for confirmed cases and the ASHA ensures that they are regular at their treatment and continue their follow up visits at the PHC.

What is heart-breaking is that the ASHA has been working on leprosy in the absence of having received any incentive to be paid to her against her work. The work that she has been doing is based on her self-motivation that has been instilled in her. From the tracking records at the PHC, it is observed that the confirmed are followed up and are mostly regular for treatment if living in the same area.

Screening of hidden cases through School Health Programme

School health programmes are conducted every month to cover all schools (mainly Government schools) within the coverage area of the PHC. The PHC MO covers all the schools twice a year. Skin/patch examination is one of the components. The DPMO/DC are involved in raising awareness to the students by showing pictures of skin patches, and are asked to come forward for an examination if they have any skin patch on their body. ANM/ASHAs and sometimes lady teacher's help in examining the patch in girl students.

Karalapadu and Durgi PHCs of Gurjala division cover 23 and 21 Government schools respectively. The same school is revisited every quarter. Vemuru, Inturu and Yedlapalli PHCs of Tenali division visit 63 schools both primary and high school. In Inturu, one girl (PB) was diagnosed with leprosy during the school health programme.

Katuri Medical College (Private) has introduced an initiative to screen 5,000 students of Government and private schools for skin and other problems. KVP colony and Thuphan Nagar UHC cover 10 schools each through yearly visits. G. Mupalla and Krosuru PHC are covering 108 schools of Amravati division by visiting 4 to 5 schools every month.

Two schools in Tenali (urban) division were visited as part of evaluation. Koganti Sivayya High School is a Municipal School run by local civic body. It has a strength of 625 students. Mr. Prabhakar Rao DPMO, Rama Krishna DC, Victoria Rani and Deva Sahayam of Lepra India visit the school for awareness raising and screening. Two PB cases were diagnosed during school survey - 12-year old boy on October 15, 2016 & a 10-year old girl in 2015.

During the school survey, a mass leprosy awareness is done using pamphlets either during school assembly or during other convenient time for the school. Following the awareness session, each student is examined thoroughly class by class. Girls are examined separately with the help of lady staff, school staff. The drill master/Physical Education Teacher helps in maintaining discipline throughout the process.

Similarly, the evaluation team also visited Chenchu Rama Naidu Government School. Mr. Uma Maheswara Rao (National award winner) was the Head Master, but was not available during the evaluation visit. Mr. Jayakumar (Maths assistant) was present and explained the process. The same team of the previous school visit this school as well. One boy of 9th class and a girl from 10th class were diagnosed to have leprosy patch and were put on treatment through the PHC.

Jawahar Bala Arogya Raksha (JBAR)

The Government of Andhra Pradesh has launched a School Health Programme across the state on 14 November 2010, under the name of Jawahar Bala Arogya Raksha (JBAR). As part of the scheme, Rajiv Vidya Mission (RVM) would train teachers to recognise students with health problems. The Women and Child department will provide nutritious food to students suffering from malnutrition, and the Medical department will provide treatment free of cost.

Skin/patch examination is not part of the programme objectives. However, it can be linked based on two of the programme objectives namely, 1) Treatment of all minor ailments, including malnutrition, scabies, lice infestation, etc.; 2) Referral of children requiring secondary and tertiary

care to the appropriate facility for Specialist review, appropriate investigations, treatment of the disease and follow-up.

2.2. Community interventions for early disability identification and disability limitation

Description	2014 (Jan- Dec)	2015 (Jan- Dec)	2016 (Jan- Dec)	2017 (Jan - June)
No. of patients getting home-based ulcer care	143	123	104	32
No. patients developing new ulcer decreases	13	10	16	10
No. of ulcer cases healed	207	225	253	109
No. of ASHAs referred suspects	318	386	422	305

*Data from MIS

Beyond early screening, the project is promoting early identification of disability and promoting stimulative physiotherapeutic exercises to strengthen nerve function and reduce effects of disability. In addition, reconstructive surgery is carried out for those requiring surgery. Self-care as an approach though promoted by the project to reduce injuries is not on the top of the mind strategies. People were less forthcoming with the processes such as moisturising the skin using coconut or other oils prior to carrying out the exercises of the hands and feet.

In the villages visited, almost all people who were interviewed were aware of the exercises that need to be carried out. Almost 62% were carrying out them out, however, it is difficult to ascertain if they are doing it on an everyday basis and an observation of their feet and hands suggest that they are not regular at self-care. Around 12 persons had florid ulcers. What is to be noted is that we did not witness any person wherein the ANMs had carried out treatment of ulcers at the village level. On the similar note, only one ASHA among those interviewed had physically observed on how a person with leprosy was carrying out bandaging or self-care at the household level.

Almost all people requiring foot and hand care among those we met knew about 'soaking' as an important part of self-care. Soaking of feet and hands in water was known to all people who were interviewed. A cursory exercise was conducted to check their hands and feet to know how much it is implemented by people with leprosy. Of the 58-people met, almost 40% requiring self-care were carrying out self-care. However, most of the people carryout self-care sporadically, not every day.

It is difficult to ascertain the functionality of the self-help group. Two self-care group could be met and in these villages, 4 to 5 people meet once a month to carry out self-care. However, our learning is that operationally it is challenging to get people together at one point and when they

do so, to carry out self-care. One of the groups was on microfinance and they met for loans matters that took priority. Another group met as

2.3. Geographies in Leprosy

The project strategy is planned to reach people living in the general community and provide them services within the communities. What is noteworthy is that all people whom we met were living within the villages. People living within the general community area did not express the desire to move into colonies or had made attempts to do so. The project geography had areas that had colonies and we visited them to understand the services provided as part of NLEP:

Bunny Nagar colony comes under Yedlapadu PHC of Amravati division. It was visited to know the status of medical services provided through PHC as outlined in NLEP, and also to understand the impact of educational and rehabilitation services provided through various stakeholders on the quality of life of people living in the colony.

Thirty households with 150 people are living for the last 10 years in Bunny Nagar colony. They were given free 'Patta' (legal land document) by the Government to build houses through Indira Awaaz Yojana. Indian Rupees (Rs.) 100,000 (1 lakh) is given by the state Government to build houses for each family. Of which each family should pay Rs. 30,000 back to the Government. Since they have not yet paid Rs. 30,000, the Patta is with the Government.

Children from the colony are going to the nearby Government school; 2 children are given free education through the GRETNALTES School; one youth has received vocational training from The Leprosy Mission, Vizianagaram; one is pursuing Bachelor of Technology/B.Tech; and two others are doing diploma courses in a Polytechnic.

Water supply is through a tube well dug by a local donor. Elderly people are receiving old-age pension (Rs. 1000) and others are getting disability pension of Rs. 1500. They are receiving free food ration for each household through AAY (35 kg rice).

A Doctor and a Nurse/ANM from a nearby PHC visit the colony every week for any health-related ailments and for dressing ulcer. The inmates visit the same PHC for all their health needs.

People affected leprosy live within their family and their children are getting married from others outside the community. While interacting with the daughters-in-law, they expressed they had 'fear' in the beginning of the marriage, but later accepted it as part of life. A general description of leprosy and its transmission; it is a disease, and not a curse was given by one of the project staff.

There were other people in the community (non-leprosy background) living around them, and have constructed house and are living close to the open colony. People affected by leprosy in the colony work as security guards, agricultural labourers in the nearby town. The community as a whole happily said that they experienced no stigma and discrimination, and their quality of life is the same as others living in the nearby villages.

2.4. Stigma and discrimination

Among the person we interacted, many of the persons met expressed that they did not face discriminatory practices in their familial space. As most of them were living within the household,

they were part of social and other familial events. Many of them were attending social functions. Daughters in the families were married. We did not meet any person who had to give in the outhouse or in a shed outside the house. Families in some situations had not revealed that the child we met was having leprosy. We visited a child with leprosy. He was at school and the father had informed that school that the clawing was a result of an injury. There was one teenager we met who had delayed treatment due to self-stigma and returned with G2D.

2.5. Civic rights and social benefits

GRETANALES and the General Health System have done a phenomenal effort to connect people with leprosy to civic and social benefits. Of the 3053-identified people, 2442 are reportedly linked to some welfare scheme, mostly pension services. All people with leprosy that were interviewed had an Aadhar card, voter identity and a ration card. Hence, all the respondents had access to the food supplies given by the government ration program. Those needy had also got grains under Anthyodaya Anna Yojana (AAY) and this was almost 99% coverage among those who were needy. People with leprosy were largely contributory; however, involvement in gainful employment was around 55%.

The Government intends to provide welfare services using JAM, the triad of Aadhar card, a bank account (Jan Dhan) and the mobile. Among the persons interviewed, 63% had bank accounts and only 22% had access to mobile phones in their households. There is a possibility of several persons with leprosy falling between the gaps especially when the government plans to carry out direct of transfer benefits.

3.2 PROVISION OF BEST PRACTICE TERTIARY CARE IN THE REFERRAL HOSPITAL

Description	2014 (Jan - Dec)	2015 (Jan - Dec)	2016 (Jan - Dec)	2017 (Jan - June)
No. of Leprosy patients reported through the Private Practitioners	10	18	29	21
No. of cases with reaction / neuritis identified and treated	18	42	38	19
No. of patients provided treatment in each of the OP/IP categories	3096/601	2856/581	2794/568	1163/233
Admission and readmission for ulcer cases	29/437	24/414	19/403	8/168

3.2.1 Referral Mechanism

No referral register was available at the PHC for documenting forward and backward referral (two-way). Difficult to diagnose cases are usually referred to Guntur Government Hospital (District Hospital), and complicated ulcer and RCS are referred to GRETNALTES, Morampudi. The link between forward and backward level is not seen. It is mostly one-way referral.

No simple ulcer was referred to GRETNALTES last year from the PHC and the UHC visited. The MO said that chronic, non-healing and complicated ulcers are referred, and simple ulcers are managed at home. Dressing materials are given to the patients to do dressing at home, and are supervised by ANM at the community level. Sometimes, ANM does dressing at home, and at PHC by Male Nursing Orderly/MNO. The ANM/MNO were comfortable touching/holding the leg of leprosy patients while dressing. Stigma and discrimination is not detectable.

The skills in dressing ulcer by ANM were observed in Vemuru and Yedlapalli PHCs where patients with ulcer were present on the evaluation day. In Vemuru, simple ulcer dressing with no callous removal was done by ANM. The ANM did a 'fair' dressing of ulcer with just gauze bandage. No resources material for SSO/tub, Scalpal handle & blade, dressing materials in the recently upgraded PHC. On the other hand, MNO of Yedlapalli PHC did a 'good' dressing for simple ulcer. If the scalpel handle and the appropriate blade was available, he could have done the trimming of callous / nail better.

It was told that 15 patients were referred for RCS from the PHCs and UHCs visited except G. Mupalla PHC where no RCS referral was done. No record of patient referral for RCS (data source) is available at the PHC.

2.6. GRETNALES Referral Mechanism

No referral register was available at the PHC for documenting forward and backward referral (two-way). The MO uses outpatient slip for referring patients to GRETANALES / DLO / Medical College. Ulcers, mostly complicated and RCS are commonly referred to the higher level. GRETANALES uses a format /referral slips to refer patients to PHC for further treatment. In Santhi Ashram PHC, a file for referral slips from GRETANALES was available. The link between forward and backward level is not seen. It is mostly one-way referral.

Regarding referral for ulcer cases, the MO said that chronic, non-healing and complicated ulcers are referred, and ulcers in remission and simple ones are managed at home and at PHCs. Dressing materials are given to the patients to do dressing at home, and are supervised by ANM at the community level. Sometimes, ANM does dressing at home, and at PHC by Male Nursing Orderly/MNO. The ANMs/MNOs were comfortable touching/holding the leg of leprosy patients while dressing. Stigma and discrimination is not detectable.

It was told that 9 patients were referred for RCS from the 7 PHCs visited except Peddipalem PHC where no RCS referral was done in years. No record for patient referral (data source) is available at the PHC.

2.7. GRETANALES Referral Hospital

This is the only tertiary leprosy referral centre for Guntur district providing outpatient, inpatient services for leprosy including ulcer care, MCR, RCS and Socio-Economic Rehabilitation. There is a full-time Medical Doctor who takes care of the outpatient department of the hospital. An experienced, visiting reconstructive surgeon does RCS for GRETNALTES on a monthly/weekly/as per need basis. The APMO/DPMO/nodal person identifies those requiring RCS and the list is sent to GRETNALTES through the DLO office. The date for surgery is fixed based on the convenience of the visiting surgeon, and is shared with the APMO/DPMO/nodal person and the DLO Office for

them to send the cases accordingly. All patients for RCS go through pre-operative and post-operative physiotherapy. Seven to ten days or more of pre-operative physiotherapy is mandatory for good results. This duration should not be compromised. Similarly, post-operative physiotherapy guidelines should be strictly adhered. The Physiotherapy unit has a trained Physiotherapist and basic resources for leprosy Physiotherapy.

Patient charts were incomplete. The outcome of RCS in terms of cosmetic and functionality is 'fair.' However; it can be improved with better physiotherapy techniques, and spending more time with patients. The time spent by the Physiotherapist is of concern as he is overseeing other areas in the hospital.

A trained and experienced dresser does ulcer dressing in the hospital. However, aseptic guidelines are not strictly followed. The dresser does not wear gloves. Dressing kit is not sterilized, and the same kit is used for all patients. The wards were maintained clean and tidy.

An experienced footwear technician manufactures MCR footwear. The quality is good. Tyre sole is being used to protect feet from external injuries and thorns. This is a good feature absent in the MCR footwear available in the market. It was told that patients complain about excessive weight of the footwear for non-compliance. However, this cannot be a valid reason as the average weight ranges between 600 and 750 grams, which are well within the range of any market footwear. Further, the safety feature cannot be compromised!

Four inpatients were not having MCR footwear. It was told that MCR footwear is not given to the inpatients through the referral hospital, and is given through the PHC as per the (annual) demand. The 'supply chain' mechanism for MCR provision seems too complicated! It was observed that inpatients 'walk on ulcer' which the hospital staff should take extra effort to educate and ensure that ulcers are 'rested' to accelerate healing. Adequate mobility aids (crutches, walkers, wheelchairs etc.) should be available for inpatients. The time-tested method of 'Below-Knee cast with Bohler Iron' for ulcer healing should be followed.

Patient charts (paper) of all patients who visited GRETNALTES with first and follow-up visits are well maintained in the medical records room.

2.8. Role of Medical College in Leprosy

Katuri Medical College/KMC is one of the private medical colleges in Guntur offering postgraduate (Masters - MD/MS) and undergraduate (Bachelors' - MBBS) courses in Medical Sciences. The Medical Council of India recognizes the college. It is affiliated to the NTR University of Health Sciences, Vijayawada with collaboration and close links to the International Medical and Technological University.

The Department of Dermatology, Venereology and Leprosy deals with diagnosis and management of skin diseases, sexually transmitted diseases, leprosy as well as skin manifestations of internal diseases.

The evaluator met Dr. Senthil Kumar, Assistant Professor in Dermatology who was working for the last two and a half years. Mr. Prasad, APMO; Ms. Ratna Manjari, DPMO, Mr. G. Ramesh, Divisional Coordinator and Mr. Shivakumar, Physiotherapist, GRETNALTES were also present.

KMC detects leprosy from outpatients visiting with various skin ailments. They get referral from nearby PHC and UHC as well, but the majority is by voluntary reporting. Since it is a teaching institute, a detailed examination of leprosy (including biopsy, smear) is worked up by the postgraduate students in dermatology, and is presented to the senior dermatologist before arriving at a diagnosis and course of treatment. Once leprosy is confirmed, they are referred to the PHC concerned for treatment through the DPMO who visits KMC every Wednesday for the leprosy clinic. However, some private patients (about 25%) who do not want their disease to be revealed citing stigma and discrimination are not referred but treated at KMC. The DPMO is notified of all cases diagnosed in KMC. The MDT regime, some of the dermatologist feel, is inadequate, and they continue the drugs beyond the WHO schedule of 6 or 12 months.

There is no (need of) case validation for cases diagnosed in KMC. No MDT stock is kept in KMC. For private patients, the drug combination based on WHO schedule is given, and no blister calendar pack is given. All reaction and neuritis are managed in KMC using steroids, Clofazamine etc. There are 2 beds reserved for leprosy patients. Recurrent Type 2 Reaction who would benefit from Thalidomide is referred to Blue Peter Health Research Centre (BPHRC) at Secunderabad, a project of LEPRO, India.

KMC has conducted small scale, experimental research in accelerating ulcer healing using Plasma Rich Protein/PRP injections, and the results are encouraging and are yet to be published. They are keen to undertake or be a part of multi-centric Thalidomide trials for which they need guidance were advised to contact the ILEP Research wing for collaboration in research.

No RCS is being done in the medical college. They refer cases to GRETNALTES. One patient was referred last month. MCR footwear is not available with KMC. They refer needy patients to a private centre selling MCR.

3.3 REGARDING SCHOOL HEALTH PROGRAMME, KMC HAS INITIATED TO SCREEN 5,000 STUDENTS OF GOVERNMENT AND PRIVATE SCHOOLS FOR SKIN AND OTHER PROBLEMS. DR. SENTHIL KUMAR SAID THAT CHILD CASES IN THE LL SPECTRUM CONTINUES TO GET REPORTED WHICH IS A SIGN OF RECENT TRANSMISSION OF THE DISEASE IN THE COMMUNITY

— A LONG ROAD AHEAD FOR ERADICATION OF LEPROSY! PROVIDING TECHNICAL SUPPORT IN TERMS OF CAPACITY BUILDING AND MONITORING FOR THE PROGRAM

3.3.1 Training

Description	2014 (Jan - Dec)	2015 (Jan - Dec)	2016 (Jan - Dec)	2017 (Jan - June)
Refresher training conducted	83/85	86/92	84/92	90/92

3.3.1.1 Medical Officer:

All MOs have received one-day training in leprosy given by the DLO office at the beginning of their career in the last two years except MO from Durgi and Inturu who have received training long back. Training status of MO from G. Mupalla and Thuphan Nagar is not known, as they were not

available during the visit. The dermatologist at the CHC and the private medical college did not receive any training from the DLO Office, as they are subject specialist in leprosy.

3.3.1.2 DPMO/APMO:

Two APMO/DPMOs have completed 6-month Para Medical Worker/PMW course in GRECALTES, Kolkata, and another staff has done Non-Medical Assistant/NMA training in leprosy from Kolkata. Recently, a one-day refresher training was given to the APMO/DPMOs in 2016/17. 9910066602

3.3.1.3 ASHA / ANM:

ASHAs were given (2 to 3 hour) orientation in leprosy during the monthly review meeting of ASHA (ASHA day) by the DPMO/DC. The ANMs received a two-day training in leprosy given by the DLO office.

It was observed that ANMs (and by MNO wherever available) do ulcer dressings in PHC, and at times in the home of people affected by leprosy. But they were not trained in dressing leprosy ulcer. There are few key points to be followed while dressing leprosy ulcer: soaking should be done prior to dressing; no cotton (only gauze) to be used; callus, nails should be cut; probing, deep dressing for sinuses, Magnesium Sulphate Glycerine Acriflavin / MSGA dressing etc.

2.9. Monitoring and Supervision

The leprosy program at the PHC level is monitored by the APMO (where available) or by the nodal person who is the supervisory staff of 4 to 5 Sub-Centers within the PHC. The work of ANMs at the sub-center are being supervised regularly. APMO submits the ATP to the DPMO. ATPs of supervisors are approved by the PHC MO on a monthly basis. Demanding high accountability from the ASHA is not considered as she is not a health care staff but a volunteer. There is no monitoring and supervision checklist of tasks available of what needs to be assessed, action taken and reported.

In general, it has been observed that monitoring and supervision is primarily intended for collecting data and reporting. The monthly meetings are a crucial component of monitoring and supervision where the data is presented, clarified and reported to the district level. It is mostly one-way (bottom-up), and the feedback (top-down) is for clarification of the data, and not on analysis.

Similarly, the DPMO supervises the PHCs and reports to the PMO. The DLO and his team – Medical Consultant and PMO primarily are involved in the divisional level supervision. Lastly, the role of community health center covering a population of around 100,000 is not clearly found in the evaluation. It was told that the next level from PHC is directly to the district level, and the intermediate CHC does not exist in many places and are usually bypassed. Some PHCs have been upgraded to be CHC but are not adequately equipped with man and material resources to play the intermediate role. Similarly, Area hospitals are not part of the link between PHC and the District.

2.10. Joint field visits

Joint visits are visits that are made by the DLN and the NGO. They are primarily made for further assessment of suspects who have dropped out of service after initial screen, midway during

treatment or when treatment gains are not visible. During these visits, the team meets the people and develops an understanding on their progress, needs and requirements. These visits are carried out consistently as per need, however, the purpose governs the visit and it often operates from the reality of lack of adequate hands with the District leprosy unit. Rarely does the joint visit get carried to low prevalence pockets or for the purpose of only monitoring field operations.

2.11. Digitalization of data

GRETANALTES has been provided with tablets to digitalize the monitoring data. There are some concerns on the tablets as they were slowing down and some of them have processing issues as new information was added. There may be issues of synchronization and storage that needs to be addressed with the staff members. There are concerns from the community as getting consents for photograph when it comes to younger girls and newly married for the fears of being identified. The project is lagging behind on data entry.

3. Management capacity of the partner

3.1. Human resource as capital

The project has appointed 6 Divisional Coordinators (DC) reporting to the Project Coordinator who in turn reports to the GRETANALES Executive Director. Each Divisional Coordinator is responsible for 15 to 20 PHCs. The project team has been long standing (16 to 34 years of experience in leprosy). Several of them have received the Para Medical Training during the course of work at GRETANALTES. The Project Coordinator has an additional training on physiotherapy which is an added advantage to the program. The longstanding staff members are an enriching value addition that has led to linking people in the need of services to the hospital. The team also draw additional support for RCS through the GRETANALTES hospital team.

The project team views the project primarily from a service delivery mode where people are identified and linked to health services, mostly RCS services at GRETANALTES. The focus of the project has been on providing training to the ASHA and PHC to identify people through community and school surveys for treatment of reactions or for confirmed PB and MB cases or for ulcers. While self-care is one of the thrust focus areas, the prevention of impairment and disability is not on the top of the mind activity. Note-worthily, the team considers linking people to social entitlements as an important component of their role and is reflected in the large section of the people covered under the pension scheme.

The teams had a weekly plan for visits which governs their focus for the visiting the PHC and villages. During their visit to the PC, the project staff members conduct training for the PHC and/or ASHA. On a monthly basis, the team has a review with the NGO Chairman where they share their progress on work.

3.2. Coordination among FAIRMED, GRETANLTES and District Leprosy Unit

The three partners have been working in synergy for the CDLCP project planning and monitoring in collaboration. The District Leprosy Unit and the GRETANALTES has benefited by the presence of a National POID Manager being co-located at the Districts for smooth flow of budgets, technical handholding, managerial supportive actions and improved donor-NGO relationship. The effort of

the collaboration has resulted in extending pension program for people with leprosy through the combined efforts of working with the social welfare department.

The National POID Manager has also extended support to the District Leprosy division as NLEP Coordinator for the State. He is an important link to flag local issues such as supply concerns in drugs and MCR to the system and encourage facilitative actions for the resolution of issues.

The Country Office has meticulously worked on designing a structured program that has contributed to the sound implementation of the program and the timely release of funds. In addition, put in place backstopping mechanism which has provided periodic technical inputs for improvement of program. The Country Office has supported the development of the electronic data management system which as of now is in the process of streamlining. Once the teething problem are resolved, it will have significant advantage to the program. The District Leprosy Office has expressed interest in the data and have said would be greatly benefited for use in their decision making. However, as the system is in process and not completely rolled out, the process for sharing needs to be thought through and negotiated.

3.3. Effectiveness

The District knowledge of the system on the role of the NGO is fairly clear and they are able to relate to the role as a technical partner especially in promoting early case detection and the reduction of disability. They are able to see the NGOs role in screening survey as supporting in saturating coverage by handholding the ANM and ASHA, and building their capacities through training and capacity building especially in nerve function test. However, the leprosy unit is facing the hard reality of shifting their roles to the general health system which has resulted in the government's decision to curb fresh recruitment when leprosy workers retire. This to some extent results in the district leprosy unit as seeing the NGO as an extended arm to fill the gap in manpower.

The system finds the NGO effective in their functions and jointly, they have been able to address and strengthen the leprosy care (60%) through counselling, motivating people and supporting behavior change communication. The General Health System has been able to largely lead the processes in screening communities through the ASHA, problem solve when they do not report, confirm and treat if found affected. The project is aligned with the National strategy and has contributed to the facilitating its roll out.

The project set the current phase based on the evaluation of the previous phase of intervention. The intervention has not seen a lag in initiation as the movement from one phase to another has been well managed. The continuity of staff has ensured that the flow and tempo is maintained. The advocacy for promoting MCR for those with leprosy and the incentives for the ASHA was areas that the project was not been able to reach a logical conclusion. The failure here may not be of the NGO but of the overall leprosy strategy in the Country.

The project had committed to developing standards for operational processes and the operational research. However, the research studies could not take off the ground. The Country Office explored potential partner but however, the plan could not be materialised. However, there was

a possibility of flagging the same to the donor to see how this deliverable could be achieved and thereby contribute to the National and State programs.

The partnership between the district leprosy unit and GRETANALES is one of mutual comfort and respect. There are forums to discuss issues, however, it is difficult to discuss on the quality of efforts in the absence of documentation of the minutes of the meetings. The project has been able to build the confidence in the community and make itself as distinct yet a collaborative unit of the District Leprosy Program.

3.4. Efficiency

The program has been successful to a moderate extent in shifting the vertical leprosy program to a General Health System through training and building competencies of the ASHA, ANM, the leprosy nodal person and the district leprosy unit. Grade 2 deformity among the suspects is dismal and this is most likely due to the regular screening for suspects that is carried out by the ASHA in the intervention villages, the early initiation of treatment, the strong follow up for those dropping out of treatment or not initiating treatment, the promotion of self-care.

The donor-NGO relationship is one of mutual respect and the long-standing relationship governs the functionality and goal directedness in the relationship. The commonness of purpose and the years of working together has helped maintain professional considerations. The evolution of the activities over the different project phases during the years of engagement has been possible given their appreciation of the purpose.

3.5. Sustainability

The intervention is largely owned by the system and has been internalized by the District Leprosy Unit. The General Health System is at ease to treat those with signs of leprosy, are comfortable in the spaces that people with leprosy use and have no hesitation to sit beside them or treat them. The biggest barrier to stigma and discrimination in health care is to a large extent addressed and that has made it provide the confidence that people with leprosy can have access to services in the general health system. Working with people living in communities and identifying before disability sets in has reduced the need for people to move out of mainstream society.

The project has shown that it is possible to effectively get the General Health System to respond to leprosy. The seeds of sustainability have been set however, unless and until the state and district program provides the push to incentivize the ASHA, streamline the supplies of MCR, drugs and self-care supplies and promote self-care as an important part of the intervention the momentum cannot be sustained.

Revisiting the Theory of Change

The project theory of change is grounded on bringing about improvement in the quality of life among people with leprosy by building capacity of the general health system on prevention of impairment and disability. The project intended to improve the early detection of people affected by leprosy through intensive search at the community level through survey and through one to one contact by the ASHA and the ANM at the village followed by contact tracing in the

neighbourhood of the identified confirmed person. To achieve this, the project has trained the NLEP staff located at the PHC enhancing their knowledge and skills to identify and reduce disabilities in the early phase of the infection.

While the theory of change has been robust and followed the trajectory of change, there are operational issues that has weakened the theory of change at the implementation level. The ASHA, the NLEP nodal persons at the PHC, the Medical Officer at the PHC and the District NLEP team have collaboratively worked to con, they had promoted monthly screening of fixed number of the community members as a strategy for survey. This is possibly to make the survey approach achievable and simple for the ASHA, however, that has undermined the potential and purpose of the survey to reach every person/household on a monthly basis. The presentation of suspects with disability is likely to have resulted from the rather weak mechanism for monthly contacts by the ASHA. The day to day field visits being limited to only a section of the community would elicit suspects in the said number of households.

The projects rests on the fulcrum of building the capacity of the NLEP staff to prevention impairment and disability and is set on the premise that the trainer is better informed than the recipient. The theory of change has considered capacity as a give-in and has not given adequate importance to strengthening the capacity of the existing staff nor has the project on its own taken that mantle.

The thrust focus of the theory of change is POID, however, the implementation vested energies in RCS. The importance of self-care was not explicit and hence probably received lesser importance. The importance of physiotherapy as a strategy to deal with simple deformities did not see wide and robust reflections at the community level leading to an overdependence on RCS in case of disability.

The referral centre is a good anchor-point to treat advanced ulcer cases; however, this has at times led to the PHC referring ulcers that could be managed at their level to the referral centre. It is a challenge for the referral centre to reject the person as it would be lead to aggravation of the ulcer if and when the transfer the case immediately. What is required at the government system is an intermediary service on the lines of the tried and tested LRCs in the State of Maharashtra. This would enhance the capabilities of the government system for a sustained response system less dependent on the private services.

The government has promoted the LCDC and the Sparsh campaigns that have added valuable in the drive to early identification of suspects. This is a recent initiative and has great value to provide visibility and involvement of the frontline workers to provide momentum to the screening of suspects. The NLEP program promotes monthly screening program that is the most effective mechanism the is currently available to identify cases before disability sets in. In the background of the new campaign strategies, the monthly screening needs to be promoted at the current momentum.

The Nerve function test is getting promoted within the program, this, however is skill based and in the contexts of health where there is a high turnover of staff needs greater iteration and emphasis within the program. The confidence building among health workers can go a long way

in building mechanisms for medical personnel to carry out nerve function test, an important component of POID.

The theory of change laid the foundation for operations through a program management system led by a Program Manager. This is commendable, however, at the operational level, it culminated into a shared Program Manager across the two districts program and overtime it did not translate in practice. This has been the critical missing factor and needs to be revisited in the next phase of the project.

The Theory of Change proposed is robust and has proved itself in bringing about early identification before the onset of treatment and appropriate treatment in identified cases. As the thinking progresses to developing the next phase of the project, it is important to build upon the current theory of change to bringing about results for impact within the dynamic scenario in which POID is instrumental.

4 INTERPRETATION, CONCLUSION & RECOMMENDATIONS

INTERPRETATION, CONCLUSION &

RECOMMENDATIONS I. Proposed Next Phase

The rapport built up by the GRETNALTES with NLEP staff at all levels is commendable and it is yielding positive results with respect to POID through the PHC network. The collaborative partnership has the potential to grow from “passive collaboration” to “working together” to the proposed “weaning off” stage of letting them to ‘do on their own’ and support them as necessary. This shift has been attributed and coinciding with two different phases of POID interventions carried out through GRETNALTES namely DISPEL/POID Pilot and the current CDLCP project.

However, the evaluators conclude based on the analysis of the NLEP indicators over time that the project has not reached a point of exit. Much work is needed in terms of supporting the district, divisional and PHC level healthcare system in further reducing the disease burden due to leprosy with a targeted (results-based) approach.

This would mean that the project (before the next phase) identifies, documents/maps the strengths and weaknesses of each PHC in terms of their performance, and technical support is given only on the weak areas rather than uniform all or none support to all PHC. The next phase should also focus on building partnership and empowering ‘like-minded’ CBOs who could play the supportive role to the health facilities. Strengthening DPO of people affected by leprosy and others for programme and policy advocacy, involving private practitioners for leprosy training and reporting would bridge the missing links in the health care delivery system.

Primary Health Care/PHC has taken up POID work in a large way. PHC staff structure is adequate to carryout POID activities from the community/sub-centre level to the PHC including monitoring & supervision at all levels without the dependency of NLEP/vertical staff (DPMO/APMO) at the PHC level.

Since the number of vertical staff (NLEP) staff within the general health care system is shrinking with staff getting retired and are not being replaced, the State Government’s strategy of having a nodal person for leprosy activities in the PHC where there are no APMO/DPMO is good. However, it was told/observed that in few PHCs where there are no APMOs, no nodal person has been identified. Currently, the role of the nodal person has been limited to reporting leprosy activities only. Therefore, empowering the nodal person with clear roles amidst his/her primary responsibilities is needed.

Recommendations

1. The next phase of the project with a targeted, results-based approach has been recommended. Key results for each POID category, Health facility level, NLEP staff, PHC staff, Supervisory staff should be developed for capacity development, resource supply, and for performance & outcome monitoring including reporting.
2. PHCs in each division to be graded under 5 parameters - leadership, technical capacity, man and material resources, monitoring & supervision, and documentation & reporting. Based on the

assessment, the project should determine the type of support to be given to each PHC with an effective strategy.

3. The project should move away from the “DPMO/APMO” era, and work towards preparing PHCs to cater to the needs of people affected by leprosy within the existing/available health care system.
4. Nodal person for leprosy should be identified in PHC where there are no APMOs. The tasks of the nodal person should be developed by the state and district NLEP and shared with the nodal person. Based on that, the project should systematically equip the nodal person to carry out and report leprosy activities.
5. Campaigns such as LCDC and Sparsh should be well integrated in the district leprosy strategy and be considered as part to the program strategy to promote early identification and preventing disability, however, they should not be considered as standalone activities for detection of cases and should be promoted alongside monthly survey.

II. Role of CDLCP

CDLCP project has played a crucial role in bringing the mind-set change within the PHC system to move away from ‘just give MDT to leprosy patients’ to ‘ulcer care’ through the government health facilities that is nearer to where people live along with self-care at their homes. Currently, the District Coordinators and the DPMO/APMO are carrying the POID activities out ‘jointly’. Though the shift has been rather slow (than expected) over the years, but it is ‘on track’.

In the next phase, the project (staff) should move away from ‘activity-based’ to ‘result-based’ support. For example, in school health programme, it is no more “number of school survey conducted or supported,” but “number of child cases without disabilities detected”. Though we need the number of ‘activity,’ for planning, budgeting and monitoring, the focus or performance is on ‘results’. This support strategy should be conveyed clearly to the NLEP staff from top-down. Similarly, the project staff should be empowered to play their role clearly, and with good capacity, as the current capacity of project staff members is not adequate to bring in the change. The role of project/programme manager through planned monitoring of field activities is crucial.

Recommendations

6. The role of the project and the project staff/divisional coordinators should be clear to the project staff, NLEP staff at the district and PHC level, and to other stakeholders. Job description/tasks of the project manager, divisional coordinator should be shared with the state and district NLEP.
7. The tasks of the project staff including the project manager should be SMART and the training should be task-based, which is periodically reviewed, reinforced and monitored through monitoring and supervision mechanism of the project.

III. Ulcer Care

One of the major findings is that the available ANM including Male Nursing Orderly/MNO in some PHC show positive attitude in dressing leprosy ulcers but have limited knowledge & skills and resources. Use of gauze over cotton for dressing, MSGA over Povidone Iodine ointment, callus removal, draining sinus

and deep dressing are part of ulcer dressing in leprosy. PHCs do not have soaking tub, scalpel handle and blade, gauze bandage, MSGA, stool/chair, leg rest, dressing area etc. Self-care is not receiving the focus and attention that is desired for promoting faster ulcer healing.

Recommendations

8. The next phase of the project should aim to provide training for ANMs and MNO in GRETNALTES or through other tertiary centres. Basic resources required for dressing should be made available in all PHC.
9. Sub-centres should be built as points where people can access self-care material and this should be promoted among people with leprosy.
10. Leprosy referral Centres can be established to augment the services for people with leprosy through the general health system by promotion of prevention of disabilities and rehabilitation through integrating MDT services, strengthening surveillance and monitoring at the local level, enhancing community participation and social communication as part of a single strategy.

IV. Documentation

Documentation is a weak link of the project. PHC records are inadequate in documenting POID activities in their health information system. NLEP guidelines should be followed. Lack of manpower cannot be a valid reason with very few new patients (3 to 5 patients/PHC with ANCDR of 10/100,000) for follow-up/monitoring, and a fraction of them with G2D.

Recommendations

11. Specific points in documentation:
 - a. Nerve function assessment and its follow-up should be based on NLEP guidelines of every 3 months for those on MDT, and every 2 weeks for those on steroids.
 - b. Referral process (two-way) should be documented in the referral register.
 - c. G2D register should be updated having a record of all old cases with disability in the PHC/division and the new case with G2D should be added on as and when diagnosed. Record of persons given MCR should be available in the PHC records or mentioned in one of the columns of G2D register.
 - d. Patient charts of last 5 years should be kept in the PHC medical records/nodal person.

V. Capacity Building

Capacity building of PHC staff should be continued on a regular basis until they are confident enough to carry on the task. As Governments has taken over the training programs through their program, the project will need to work towards bringing quality within the ongoing monthly capacity buildings initiative of the PHC. One-off training will not be sufficient, and more on-job trainings with topics linked to their role should be planned.

Recommendations

12. Monitoring visits by the project staff/manager should accompany on-spot training in NFA, self-care, skin examination, and dressing for the PHC staff including volunteers/ASHA. And the

project manager/medical consultant should give field training in diagnosis and reaction & neuritis. Monitoring visits conducted should be independent of confirmatory test and problem-solving visits.

VI. Referral Mechanism

The referral link/role of CHC as the first referral unit (FRU) was not clearly found. Referral from Sub-Centre to PHC is good, whereas from PHC to the next level was found to be either to GRETNALTES or to the district hospital or to the Medical college (if available nearby).

Recommendation

13. First Referral Unit/FRU should be identified and strengthened with a population coverage of 100,000. The role of FRU should be as that of Community Health Centre/CHC or block level as given in DPMR guidelines.

VII. School Health Programme

It is good that school health programmes are being carried out through state-wide JBAR (Jawahar Bal Arogya Rakshak) programme. However, there is no component in JBAR for skin/patch examination. Secondly, CDLCP/NLEP staff are involved in school health survey (separately) as part of the project activity. There is no link between JBAR and school surveys by the project. It will be sustainable to integrate child case identification in school health programmes for early identification and disability prevention and for sustainability.

Recommendation

14. Programme advocacy at the state level to incorporate skin/patch examination through state-sponsored school health programme/JBAR is recommended. Focus needs to be given for identifying people with only anaesthesia also.

VIII. Monitoring & Supervision

Monitoring and supervision of NLEP programme at all levels should be streamlined and strengthened. (district to division to PHC to Sub-centre). A simplified checklist, (either integrated with other programmes or separate) should be developed and followed up along with the ATP.

Recommendations

15. A simplified monitoring & supervision checklist for PHC and Sub-centre may be tailor-made for the project based on what is developed by NLEP. The supervisory staff can give their compliance report according to the checklist.
16. A similar checklist should be followed up as part of project monitoring and reporting as well.
17. The POID Manager and the backstop mechanism can continue to play an active role to strengthen the next phase of transitioning leprosy programs to the general health system.

IX. GRETNALTES Referral Centre

The referral centre is functioning well with a full-time medical doctor assisted by a qualified medical team. RCS is being carried out through a camp approach with the help of an expert, external surgeon on a regular/monthly basis. Pre- and post-operative physiotherapy needs attention. Emphasis on 'cause and prevention' of ulcer should be reinforced to inpatients including 'resting' ulcer.

Recommendation

18. A full-time Physiotherapist who has undergone 'intensive' training in RCS is recommended. The physiotherapy protocol for RCS should be strictly followed - detailed assessment, one week to 10-days pre-operative physiotherapy - and cannot be compromised.
19. Patients with recurrent ulcer admitted two or more times in a year should be identified and a targeted approach in terms of counselling, self-care teaching, job modifications/change, home visits by the project staff should be carried out to identify the 'recurrent cause' and suggest modifications.

X. Output Based Activity

Output Based Activity/OBA and budgeting has streamlined the type of support the funding/parent agency can offer to its partners in a resource-constrained environment. It is commendable that FAIRMED has pioneered this funding method for financing leprosy services through their partners. However, the OBA can be expanded to reflect 'result or outcome-based' going beyond the traditional 'output-based' approach linking performance, quality, and efficiency parameters/indicators. The concept of health financing and its learning states that 'strategic purchasing' or 'results-based financing' is better than 'passive purchasing' of health services. 'Pay for performance,' 'capitation,' 'salaries' and 'incentives' may be worth exploring considering the challenges in financing leprosy services.

Recommendation

20. Based on the learning from OBA and the principles of health financing for Universal Health Coverage/UHC, develop a "Health Financing Policy for Health Coverage in Leprosy" that can be field tested/piloted for integration with UHC. This would serve as a model for other National programmes in the country. Being a national ILEP Coordinator, FAIRMED may consider advocating, initiating and developing a national policy on this.

XI. Program Management

The Project Operations Team has only technical people on board and it does not have an anchor with managerial competencies and is dependent on the Project Chairman for day to day matters. The concept of shared Program Manager has not materialised for the project. This has compromised adequate focus on building robust program management systems.

Recommendations

21. The future programming process needs to deliberate and explore on options to build a robust program management team for the project.

XII. Evaluation

Process or procedural documentation is a major missing link at the PHC level. Documentation necessary for monthly reporting (bare necessary!) has been more or less maintained at the PHC level. This can be justified in terms of minimal manpower at the lowest level. However, this lacks evidence in capturing the 'change' factors and processes. But, there is no mechanism of capturing the 'most significant change'. The ILEP supported district level projects can come up with simplified, 2/3 parameters/indicators at the 'outcome/impact level' rather than on 'activities.'

Case validation is done for every case by the DPMO supported by the DC, and very few times by a trained, experienced DNT medical consultant/leprologist. The probability of wrong diagnosis (false positives & false negatives!) cannot be ruled out in the absence of reliability testing.

Interactions with few new cases with disability reveal that private practitioner is a key missing link.

Recommendations

22. Evaluation of outcome of POID interventions should be done every 3-year or 5-year interval by NLEP/ILEP. Intra and inter-tester reliability should be part of the monitoring and evaluation. Similarly, Grade-2 disability among new cases should be periodically evaluated for 'missing link' in early case diagnosis. This may be advocated to NLEP and ILEP through its district, national and state forum.
23. Capacity building of private practitioners (first contact) should be advocated with the state NLEP, and it should be one of the key activities of the project.

DATA COLLECTION TOOLS

INTERVIEW GUIDE TO BE USED WITH FIELD TEAMS, PROJECT MANAGEMENT TEAM and ADVISORY TEAM

The focus of these interviews will be to understand the relevance and the fit of CDLCP interventions to the priorities of the community and the NLEP programs, to assess how effectively and efficiently the services have been provided by the project and recommendations if any for the remainder of the project period.

Relevance

1. What is the key issues affecting those with leprosy in your project area?
2. What are the main strengths and weaknesses of the project and of the public health system and infrastructure as relevant to the project area?
3. What is the nature of the partnership that you have with the community group? What kind of services is the project providing to the community group? Are these aligned to the needs, health plans and objectives of your community group?
4. In the light of the health needs of vulnerable people, especially suspects, women and children, affected by leprosy, and the existing health infrastructure of the government system, does the project intervention add any value, and if yes, then can you please describe how?

Effectiveness

5. What is your opinion on the way the project initiated activities have been able to useful to the community and to the government program? Can you share on the mission and vision of the project? The goal, objectives and activities? The results it was meant to deliver and the results it has delivered? Did you and your staff find the theory of change had interconnectedness, was appropriate and useful to bring about better quality of life among the people?
6. Are you aware of the formative work that was carried out- (baseline assessment, mapping and line listing etc) that was carried out in the project area? Can you share what you know about it? How many of you were a part of these processes? Those who were not, how did you learn about them?
7. Can you provide your opinion on the efforts that the project has put in to strengthen community and hospital based health care in your project area? Specifically, whether you think the services are adding value (with supporting data if available) and if there are any recommendations you would like to provide on these.
 - 7.1. Development of customised standards/l protocols for standardised care
 - 7.2. Training and capacity building project for health post staff
 - 7.3. Innovative practices for furthering the prevention of impairment and disability
8. To what extent have government counterparts and the community members participated in the effort to set up a layered POID program that includes prevention, treatment and reconstructive surgical intervention?
9. What has been the experience in terms of participation and frequency of convergence meetings with the District Leprosy Office? What is the nature of issues discussed and what are your views on the functioning and usefulness of these meetings? What other supports would you like CDLCP to provide to help reinforce the referral networks?
10. In your opinion which of CDCLP interventions have worked well or less well in your project area? (Probes: outreach and home visits, timely diagnosis through camps, timely treatment at the PHC and hospital, early recognition and treatment of nerve function impairment and treatment of secondary impairments due to nerve function loss through reconstructive surgery, group based exercises for disability limitation etc).
11. Are you satisfied with the way the project is being managed, in terms of –
 - 11.1. Your team members, the way you work as a team to achieve results
 - 11.2. nature of engagement with government systems and frequency
 - 11.3. project management arrangements between FAIRMED and CDLCP

- 11.4. relationship and working arrangements with government and other non-government stakeholder (only for PM/PD and NGO Advisory team)

Impact

12. Overall have there been any overall positive or negative effects of projects interventions on –
 - 12.1. the quality of health services provided at the hospital
 - 12.2. the health seeking behaviour in the community
 - 12.3. the attitude and performance of the medical and non-medical staff at the hospital and government health facilities/ field staff

Sustainability

13. What is the potential for sustainability of the interventions (i.e. community outreach, community disability groups, outpatient services, inpatient services, capacity building of teams and government functionary reconstructive surgery etc.), BCC efforts, etc.) at the end of the project?
14. What are some of the factors that can influence sustainability of these interventions?
15. Can you recommend actions that can be taken now to ensure sustainability? What should be the role of your RSIDT, FAIRMED and government to make the results sustain.
 - 15.1. Hospital and Government Medical and non-medical staff at the health facilities
 - 15.2. The focus of these questions will be to understand the perspective and experience of the hospital / health post staff of CDLCP interventions.

Relevance

16. What is the key issues affecting the health and quality of life of people having leprosy in this community?
17. What are the main strengths and weaknesses of your health facility (in terms of services, staff and infrastructure) in addressing the above needs?
18. Are you aware of CDLCP? Can you tell me what the project did - to support you, for your health facility and in the local community?
19. In your opinion are CDLCP interventions adding any value in addressing the health needs as described earlier?
20. Is CDLCP work directly or indirectly benefiting you as a provider? Is there any benefit to the people with leprosy in your opinion?

Effectiveness

21. Can you provide your opinion on CDLCP interventions to strengthen leprosy care in your area? Specifically, whether you think the following services are adding value (with supporting data if available)
 - 21.1. Development of customised standards/I protocols for standardised care
 - 21.2. Training and capacity building project for health post staff
 - 21.3. Innovative practices for furthering the prevention of impairment and disability
22. Do you feel that you have benefited from the capacity building provided by the project?
23. What are the actions that you do to prevent impairment and disability in people with leprosy?
24. Have you participated in any of the activities and trainings organised by CDLCP? What has been the experience in terms of participation and frequency of these meetings? What issues are discussed? Do you think these meetings are useful?
25. Are you aware of the referral slip introduced by CDLCP? Have you begun using it? What is your opinion regarding its usefulness?
26. How will the referral network help you and your service beneficiaries? What are the problems faced in referring patients? (Understand where and why patients are being referred)

Impact

27. How would you describe the quality of care and service delivery provided at your health facility and the quality / frequency of referral?

28. Has there been any improvement in service quality and performance of your staff after the training provided? Do you feel there has been any change in the behaviour and service utilisation by the community since CDLCP began work here?
29. In your opinion which of CDLCPs interventions have worked well or not?
30. Do you have any recommendations to improve the services provided by CDLCP?

Sustainability

31. Will any of these new systems (self-care/ referrals / community outreach) and improvements that have come in after CDLCPs work be sustained without CDLCP?
32. Do you have any recommendations to sustain the improvements?

Additional questions for Staff

1. A normal work day circle, my output in a day, how effective have I been? where do I lose time, where can I do better, what are the opportunities I have and what are the blocks that if face. What has worked and what has not worked
2. what I like about my job and how I can construct my day differently, a different Johari’s window
3. what does management expect from the Project Coordinator?

Beneficiaries

The focus of this interview will be to understand the experience of the beneficiaries of the public health system and of CDLCPs interventions. Beneficiaries exiting the health facility shall be interviewed.

1. What is the purpose of your visit today to this health centre? Were you able to get the required services?
2. Can you comment on the quality of care and efficiency of service delivery that you have at this Government health centre? In your opinion has there been any change in the quality of services over the last 3 years?
3. Were you visited at home by ASHA or any other government outreach worker? If yes, can you please describe that visit and what services/ advice you received? How did you feel at the end of the visit?
4. How many times did you visited by the ASHA or any other government outreach worker? Do you feel these visits were adequate?
- 4.1. Were you visited at home by any person from CDLCP? If yes, can you please describe that visit and what services/ advice you received? How did you feel at the end of the visit?
- 4.2. How many times did you visited by the CDLCP staff member? Do you feel these visits were adequate?
- 4.3. What activities organized by government and CDLCP in your community have you attended? What was your experience / learning in those activities?
- 4.4. Do you have any recommendations for the services provided by:
 - 4.4.1. health centre
 - 4.4.2. by CDLCP worker

Guide for management level interviews with respondents:

	Level of engagement with Project	Response
1	What types of programmatic or project-level coordination took place between the NGO/FM? Can you provide specific examples of interagency cooperation or coordination?	

2	How did AI/FM contribute to the achievement of NLEP goals? What specific initiatives, projects, interventions or advice was AI/FM able to offer towards fulfilling NLEP aims? How has this made a difference to the overall targets that we set? How did AI/FM coordinate with State Society?	
.	Relevance	
3	How has the project supported or contributed to leprosy policies or strategies? In which areas? Can you provide specific examples of good contributions?	
4	Has the project followed good practices in its work? Why or why not? Can you provide specific examples of where approaches were appropriate, well-needed and fit with national efforts?	
5	Where there were problems or challenges?	
.	Effectiveness	
6	What activities have been undertaken under the project(s) that you are familiar with? What short-term outputs have been produced? What longer-term effects were produced?	
7	How well was the project linked and work in coordination with government activities and activities of other agencies	
8	Were there significant expected or unexpected results or achievements that you know of? What were they, at different levels?	
9	What has been the scope or reach of the projects and their benefits? Who has been affected (either positively or negatively)?	
10	Has the project made a difference? To whom? In what way? Within in a limited area or in this thematic area or sector overall?	
	Capacity development	
11	The project/program have a capacity development objective. What were the activities conducted? How many functionaries were trained? Who were functionaries that were trained?	
12	Were the training needs identified? Were the manuals contextualised?	

13	Has the project/program been effective in developing capacities of those involved?	
14	Were the training programs carried out timely? Were there problems in running them? Say, timeliness of funding?	
	Program	
15	Are you familiar with the broad range of activities supported under this phase of programming framework? What do you think of program overall?	
16	Overall, what have been the results or effects from the activities you know about?	
17	Who have been the main beneficiaries of work in the project you are familiar with? At what level in the leprosy program (national/state/district), target community, others for whom services or benefits were directly or indirectly provided?	
18	Have any benefits been realized via this project for PALs, their families, communities, government system, etc?	
19	Has any significant challenges affecting project/program outcomes? How well did the project adapt to these circumstances or changes?	
	Efficiency	
20	To your knowledge, how well did the project maximise the human and financial resources? Were funds received on time? Why or why not? Were projects approved and launched in a timely fashion? Why or why not? Please provide specific examples ...	
22	Are you familiar with the monitoring and evaluation arrangements for the project/program? How well did M&E work (in your opinion) and what effects did they have on the project in which you were involved? Are the project documentation and MIS easy to understand? What types of reporting were required, and were they submitted on a regular basis? Why or why not? Did the plans and reports require add to the burden of implementing partners or beneficiaries in any way? Were they used to make necessary corrective actions? Please provide examples...	
	Sustainability	
23	Were the project/program achievements maintained and expanded over time?	

24	What was learned from the project/program? Have any knowledge and lessons been used?	
25	Would you say there is a high degree of government/local ownership of projects/programs? Why or why not? How could ownership be improved?	
Strategic relevance and responsiveness		
26	Did the project/program align with and contributed towards government plans, procedures, and policies and meet the needs of the stakeholders? Why or why not? What could have been done differently?	
27	How did the project address human rights and equity issues within the project?	
28	Were there obvious or critical gaps that the project/program did not address? What were they? What are those that will be meaningful to take forward for the future in case they continue to work forward?	

4.1 DATA TABLE

Discussion with ASHA, ANM, HV & Patients/Persons affected by leprosy

PHC	Biccaovulu	Santhi Ashram	Peddipalem	Rachapalli
Number Present	5 ASHA; 3 ANMs & 7 PAL		3 ASHA, 6 ANM & 3 HA (M)	7 ASHA; 10 ANMs
No. of suspects referred	Not known	Not known	50 suspects were referred by 3 ASHA, and 3 were confirmed to have leprosy.	20 cases suspected by ASHAs, and one confirmed.
Experiences of PHC	Good experience. Leprosy patients visit the PHC for other ailments as well. No stigma or discrimination.	Rated good by the mother of a boy who received MDT. Patients without disability rated good. People with leprosy disabilities visit PHC for other ailments, but do not expect much in terms of dressing ulcer.	Old leprosy patients expressed satisfaction with PHC services. They visit PHC for non-leprosy ailments as well.	Satisfactory

Reason for treatment delay (if any)	No delay. No new G2D case available.			
Flash card?	Yes	Yes.	Yes. By few	Yes. Only 2.
ASHA while screening	Good.	Fair – not confident	Fair – not confident	Fair – not confident
Role of ASHA	Screening & suspect referral - aware and being done; treatment follow-up - aware & being done; R&N- No; Deformity/self-care knowledge -good; contact tracing - aware & being done.			
Any issue in getting incentives?	No issues	No pending incentives	3 ASHAs did not receive incentives.	No issues.

PHC	Draksharama	Kuttukuluru	Narsapuram	P. Geddada
Number Present	12 ASHA; 10 ANMs & 4 PAL	5 ASHA; 3 ANMs & 7 PAL	No ASHA (on strike); 11 ANMs; 1 PHN; 1 CHO & 1 PAL	No ASHA (on strike); 9 ANMs
No. of suspects referred	Exact number not available. 6 to 10 referred by ASHA every month.	Not known	Not known	36 cases suspected by ASHAs, and one confirmed.
Experiences of PHC	Good experience. Leprosy patients visit the PHC for other ailments as well. No stigma or discrimination.		Rated good by the young girl who underwent treatment in the PHC.	Not known. No PAL was available
Reason for treatment delay (if any)	No delay. No new G2D cases.			
Flash card?	Yes	Yes.	Yes, with ANM	Yes, with ANM.
ASHA while screening	Fair – not confident	Fair – not confident	Fair – not confident	Fair – not confident
Role of ASHA	Screening & suspect referral - aware and being done; treatment follow-up - aware & being done; R&N- No; Deformity/self-care knowledge -good; contact tracing - aware & being done.			
Any issue in getting incentives?	1 ASHA has not got her incentive	No pending incentives	No issues, ANM said.	No issues, ANM said.

Focus Group Discussion with PAL

A focus group discussion was conducted with men and women patients admitted in GRETNALTES. A discussion was facilitated from a semi-structured questionnaire with 7 questions. A time period of 30 minutes was fixed. One of the DC helped in translation (English to Telugu). The evaluator also did the recording of responses. The total number of participants = 19 (7F & 12M)

Surgical patients = 6

Leprosy with general ill health = 1

Discussion questions/points:

1. How did they know about GRETNALTES?

Through PHC Referral – 13; Voluntary reporting – 3; and through project/CDLCP - 3

2. How many (repeat) admissions in the last year? How long were you admitted?

Two of them have been admitted twice for ulcer care in the last year. Time gap ranges from 3 months to 1 year. Six repeat admissions are in the range of 1 year 3 months to 4 years. Four patients have been admitted for ulcer care for the first time.

The duration of admission ranges from 15 days to 1 month depending on the ulcer healing.

3. What are the services provided?

Ulcer dressing, medicines, food, and SSO.

4. How much do you have to pay for the services like MCR, admission, food etc.? No payment.

5. What do you know about ulcer, self-care?

All of them said that they get ulcer because of their disease/leprosy. Only one person said anaesthesia as a pre-disposing cause for ulcer. All are aware of self-care process.

6. How satisfied are you with GRETNALTES services?

“Fully satisfied!” All of them gave 5 on 5.

7. What are your suggestions for improvement?

“No suggestions. Please continue the same!”