SWISS EMMAUS INDIA

CDLCP End Evaluation

RIDST Report

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Background

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.

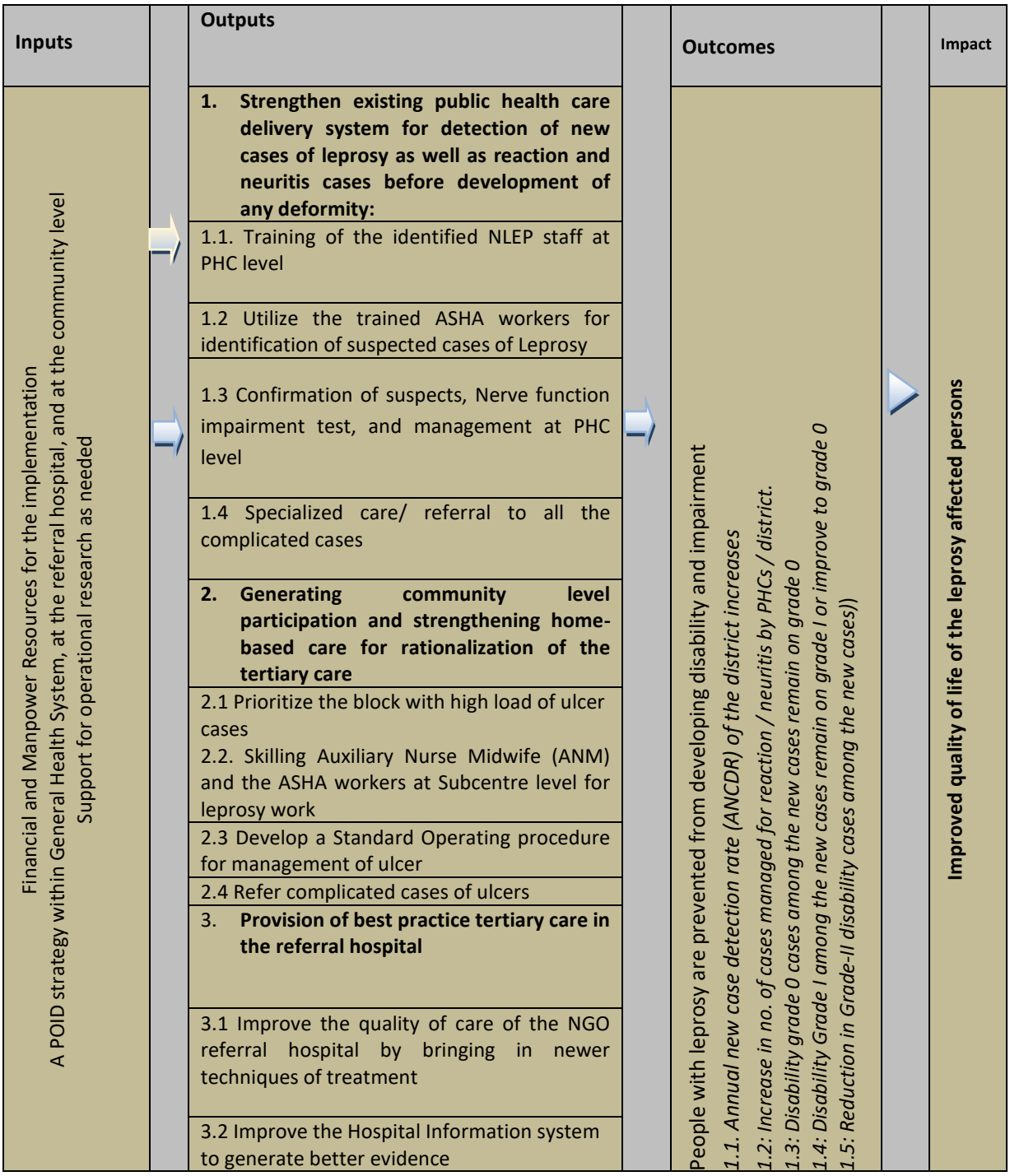
The Project

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, 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 program aligns itself with the core NLEP programmatic strategies that recommend contact survey, home-based self-care and approach, Advocacy, communication and social mobilisation and partnership with community for elimination of leprosy. Home based care is aligned with the Ottawa Charter health promotion assertion that promotes enabling actions for people to increase control over improving their health. The Home based care thus ensures that the promotes healthy lifestyles and encourages people to take control over his personal health by carrying out necessary and essential actions through self-care reducing excessive dependence on the health care service providers. This prevents person to reduce travel to PHC which are often far away from their residences and thereby preventing ulcers, reducing delay in care or further deterioration of ulcers by further injuries during travel.

The project objective is to strengthen POID services at the primary health care system, referral hospital level (OBA) and community level. It intended to undertake operation research 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).

Intervention theory of change



		program management and policy making				
		4. **Providing technical support in terms of capacity building and monitoring for the Program**				
		4.1 Project Manager to provide managerial expertise				
		4.2 Mobility support to undertake field activities				
		4.3 Incorporate field based information within Hospital Information System (HIS)				

The Evaluation Methodology

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 (i) 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.

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 Swiss Emmaus India.

Learning from the project

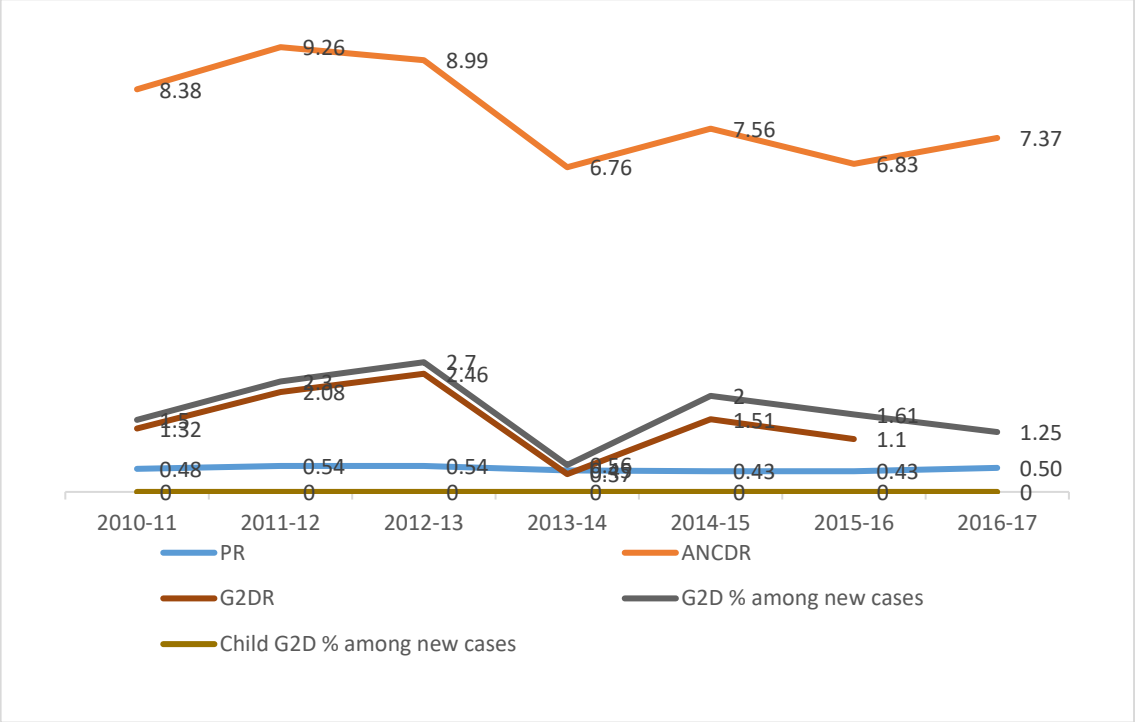
1. Strengthen existing public health care delivery system for detection of new cases of leprosy as well as reaction and neuritis cases before development of any deformity:

1.1. Trends of Leprosy over the years at East Godavari

Table 1: Trends in NLEP Indicators

E. Godavari	2010-11	2011-2012	2012-2013	2013-2014	2014-2015	2015-2016	2016-17
PR	0.48	0.54	0.54	0.45	0.43	0.43	0.50
ANCDR	8.38	9.26	8.99	6.76	7.56	6.83	7.37
MB %	35	36	38	38.9	36.84	43.39	40.65
Female %	31	33	35	33.89	41.35	33.42	28.43
Child %	17	17	17	15.6	16.29	16.98	9.98
G2DR	1.32	2.08	2.46	0.37	1.51	1.1	
G2D % among new cases	1.5	2.3	2.7	0.56	2	1.61	1.25
Child G2D % among new cases	0	0	0	0	0	0	0
TCR	99	99	96	99	98.23	97.8	98.90

Figure 1: State and district trends



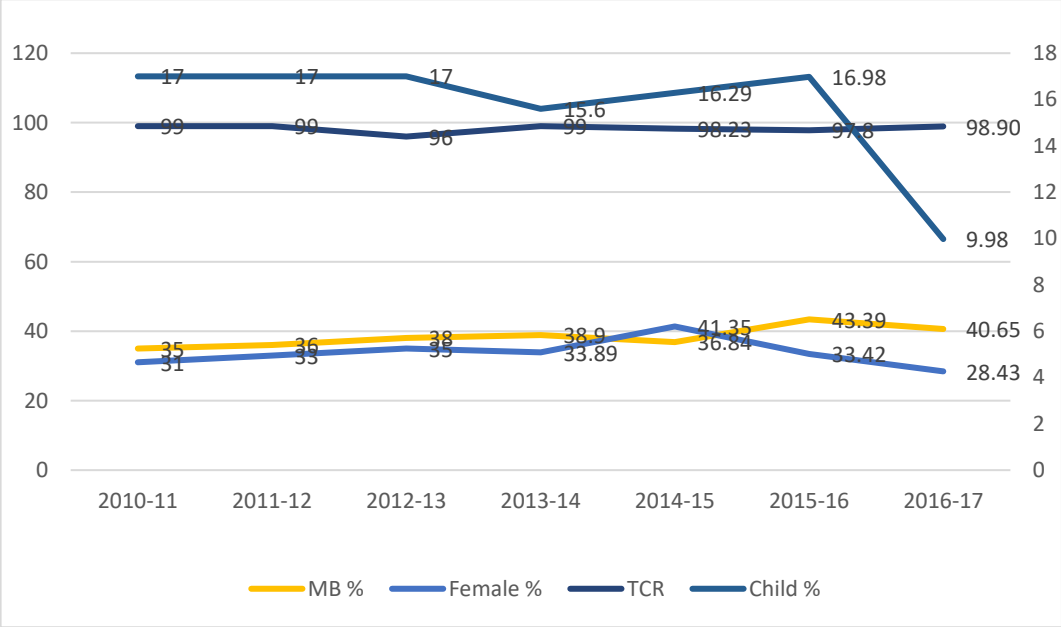
The prevalence rate of East Godavari district has reached a plateau well below the elimination target of 1 new case for every 10,000 population. This rate has not changed much in the last 6 years, and fluctuates in the range of 0.4 to 0.5 per 10,000 population. With intensified case detection activities through leprosy campaigns and focal survey in “zero PR” areas are being undertaken, new cases (though not large numbers) are continuously being detected and put under treatment.

The sudden dip in 2013-14, and following increase in 2014-15 correlates to the onset of CDLCP in East Godavari in 2014. It could be that the project has helped sustain the leprosy control activities in the district which was going downhill due to various reasons. The peak in 2014-15 and the fall in the subsequent years could mean that more hidden cases were detected including the backlog from the previous year(s).

There is a slight fall in ANCR of 2015-16 which may be due to the increased data capturing efforts by the project staff using ‘Tablets’ with innovative android software.

Grade 2 Disability (Rate & Proportion) follows the same pattern. Following the sudden increase at the beginning of the project period, the disability among new cases is showing a downward trend in the subsequent years. This is a good sign, and the project should sustain its efforts to further reduce the incidence of disability in new cases until it reaches the global target of “zero disability among new cases” by 2020. ‘Zero child case with disability’ is also a positive sign attributed by CDLCP’s support to school health programmes.

Figure 2:



MB proportion among new cases like other indicators has shown an initial climb in 2014 and a gradual fall in the following year. In other words, increasing PB proportion would mean more cases are detected early.

Similarly, fall in female and child proportion among new cases were observed with the fall in child proportion being drastic. Support to the school health programme has proved to be a successful intervention.

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

1.2. Situation of Human Resources at the General Health system

1.2.1. Medical Officer/MO at Primary Health Centre/PHC

All PHC that were visited have a Medical Officer in place except Biccaovulu where there is no MO since June 1, 2017. In P. Geddada PHC, the MO was not present during our visit.

It was good to observe that MOs at PHC are young, committed, and willing to learn new skills.

Duration of posting in the same PHC ranges between 1 to 5 years. One young MO recently got selected for her post-graduation in Medicine and will leave for her studies in a month. There was one PHC (Rachapalli) with two MOs following up gradation of PHC.

MOs (6 of 8) have a good basic knowledge in leprosy. They are capable of diagnosing suspects referred by ASHA/ANM. MOs are confident with easy cases (simple, anesthetic patch), but the difficult ones are referred to RISDT or district hospital for confirmation of diagnosis. In most cases, MOs are supported by/dependent on the APMO/DPMO for case confirmation. In 3 PHCs, the MO waits till the DNT confirms the case, and MDT is started after that.

Though MOs have the basic knowledge in Reaction & Neuritis (R&N) they are not confident of diagnosing and managing R&N. No practical, hands-on training on R&N is the main reason.

1.2.2. Deputy/Assistant Para Medical Officer (D/APMO)

APMOs were present in 2 out of 8 PHCs visited. 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. Multi-Purpose Health Extension Officer/MPHEO was identified as 'nodal person' in Draksharama PHC.

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 Program (ATP) approved by the Para Medical Officer/PMO at the district level. APMOs (where available) report to the DPMO.

1.3. Case on treatment

9 MB and 6 PB cases were currently on treatment in 5 of 8 PHCs visited. One of the villages, Gangavarum, has seen a higher PR. In one family there are three people affected by leprosy over a period of 10 years. Others have 'zero' cases until now but they cannot be classified as 'zero PR PHC' as they had PB cases in 2016-17.

1.4. Reaction & Neuritis

No R&N cases currently on treatment. In Santhi Ashram PHC, 1 case of R&N had completed treatment in 2013-14. Usually, R&N cases are diagnosed at RISDT or at the district hospital or at the medical college, and are referred to the concerned PHC to continue treatment. Referral slips are sent through the patient and are followed up by the DPMO/APMO/DC. Prednisolone is available in all PHC and are given from general stock and is not supplied as part of leprosy drugs and supplies. Clofazamine is not available in the PHC. This matter can be taken up with the SLO.

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. On an average, 10 to 15 days it takes for a case to be validated. There is no waiting time mostly as treatment is started before validation. Date of validation is not mentioned in the patient chart. Contact 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). Men and boys are examined by the DPMO, DC. 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. Case validation by the medical consultant of the District Nucleus Team/DNT and the PMO was not available.

1.6. Nerve Function Assessment/NFA

NFA at the start of treatment was done for 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. In Rachapalli PHC, out of 14 patient/pink charts examined, NFA was not done in 5 charts. In Santhigram, for a patient on R&N, NFA is done at the beginning and end of steroid regime. It was not understood that NFA is crucial before tapering the dose. In Draksharama, the nodal person could not do NFA as they were not trained in it. The same is true for all nodal persons in PHCs.

Skills of DPMO/APMO in doing sensory and voluntary motor testing were assessed either on available patients or on the evaluator. It ranges from ‘fair’ to ‘poor’. The capacity of the divisional coordinator in NFA is not very different - either the same or slightly better than the DPMO/APMO.

1.7. New case with Grade 2 Disability/G2D

In all the PHCs visited, there was no new case with G2D. In Narsapuram PHC, there was no new G2D since 2014. However, this cannot be generalized and valid to all PHCs without statistical analysis.

1.8. Deformity Register

In Biccaovulu and Kuttukuluru PHCs, the deformity register was up to date (was told). Since there was no column for date, the last entry could not be verified. The register was incomplete in Santhi Ashram PHC. This was confirmed as the names of two old patients with G2D visited at home prior to the PHC visit was not registered in the deformity register. 25 patients were registered in Peddipalem. The last update in Rachapalli was in 2006 (year was mentioned). The register was not available for verification in Draksharama and Narsapuram. 6 persons were registered in Pedda Geddada.

Documentation is not done in few cases. Here, the project staff should have periodically checked during their visit which unfortunately was not done. M&E from both Government and CDLCP should be strengthened in this regard.

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. The supplies are adequate; only in one PHC (APVVP) the UHC staff expressed the need for self-care kits. This need was related to their difficulty to access supplies from the general health system as the stock-in-charge was not facilitative.

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 dependence on RISDT is only when the ulcer is highly flared up. They approach directly or get linked to the PHC through the ASHA. In every PHC visited, the ANMs provide treatment for the ulcers at the PHC and also taught people on how to take care of the ulcers (self-care). It is observed that this group of staff have no apprehension (stigma or discrimination) in touching/dressing ulcer.

The project team had promoted group self-care at the PHC on one day of the month. The PHCs had initiated the concept of group self-care and many of the implemented it once or twice. However, it 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 one such groups at what can be said is that these meeting takes 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.

Most people we met and interviewed expressed good healing of ulcer and it was corroborated with our observation of very low (5 out of 58 persons met) who had active unhealed ulcers. This is mostly from one of the PHC where they had 4 people with active ulcers. Again, among the people we met ‘without ulcers’, their last ulcer was two to three years back across all the PHCs visited. 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.

Taking into consideration that a maximum of 5 persons needing long-term care/ulcer are living in this population set, it can be effectively and efficiently managed both in terms of ulcer prevention and its worsening at the community level with a single SMART objective/outcome of “all simple ulcers are identified and managed at the village level”. This can be undertaken as a worthwhile programmatic or interventional research to study its effectiveness.

1.11. 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 ulcers through self-care strategy and treatment of ulcers through the primary health care system. The evaluation findings show good availability of general health care staff – 5 ASHA; 2 ANM/HA & 1 MPHS for every 1000 to 5000 population. 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, 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.

The skill in dressing ulcer among ANM was observed in Biccaovulu, Santhi Ashram and Rachapalli PHCs where patients with ulcer were present on the evaluation day. In Biccaovulu, simple ulcer dressing with callus removal was done by ANM and MNO. It was good. The MO said he too does ulcer dressing. In Santhi Ashram, the ANM did a 'fair' dressing of ulcer with the available resources. Two persons with plantar ulcer were present in Racahapalli PHC where no ulcer dressing could be done for lack of essential materials. Following that, the person with simple ulcer was sent back with gauze bandage, and the second person with complicated ulcer was referred to RISDT.

1.12. 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 PMO/DLO office. The DLO estimates the order requirement to match it with the annual budget allotment. DLO office places an order to RISDT to manufacture and supply the footwear. The final product with patient/PHC identity is given by RISDT to DLO office. The PMO delivers the revised order (the budgeted numbers against the annual approvals divided for the PHC) 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. The national guideline mentions that each person has to be provided MCR twice in a year. With the NLEP program taking initiative to strengthen the supply side interventions, the role of the NGOs is now shifted to promoting preventive actions that support the use of footwear.

In Santhi Ashram, 10 persons were given MCR according to PMO this year. No record at the PHC level. No record with DPMO as he was new. Generally, MCR records are maintained at the DPMO and PMO/DLO level. PHCs do not keep a copy of it.

It was observed that at least three patients who were present during the visit have MCR but they do not wear it regularly. The reason being rainy season and the chappal will break (adhesive bond). An elderly man had developed friction ulcer in the first inter-phalangeal

space due to market/plastic chappal. Similarly, in Draksharama, 4 persons did not wear MCR for the same reason – rainy day!

The interviews with the staff suggest that only around 30% supply of footwear has been provided to the people across the PHC. Only two of the PHCs have received the full supply and this was possible because of the proactiveness of the Medical Officer. This information that only a third of the needy persons received the MCR is corroborated by the people we interviewed. Of the 58 people interviewed, only 22 had received the pair once in a year. Documentation of the distribution was also weak. Overall, 78 patients were given MCR in 6 of 8 PHCs last year. In other two PHCs, MCR footwear was given 6 months back but did not know the exact number that was given, and no record of it was available at the PHC.

What needs to be noted here is that the people received MCR only once in a year, a supply side shortage that can put several affected persons at risk for ulcers. The NGO and the government staff have brought to the notice the supply side shortfalls to the DLO during the meetings; most of these communications have been verbal and it is not clear on how the advocacy has used a systematically planned, strategic and effective approach to get the desired results.

While communities understand the importance of using the footwear and the damage it can cause when one does not use it, the perception of disadvantage on oneself is not reflective. The use of MCR footwear among people provided with a MCR pair through the government supplies is moderately low, at around 60 to 70% (15 of 33 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; they are not suitable for agriculture work, it is not comfortable, the footwear gave way, they are not aesthetic to use especially at celebrations and events and so on. What could be inferred is that 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

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. Her 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 take 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.

Success Story:

A young girl (15+ years) developed an anaesthetic patch on her left elbow in 2016. She had contacted Ms. Venkatamma, the ANM of her village on time. The ANM examined the patch and suspected it to be leprosy, and referred her immediately to the nearest Narsapuram PHC of Rampachovaram division. She was started on PB MDT, and recently completed her treatment. The large elbow patch was just above the ulnar nerve, and any delay in seeking treatment and diagnosing it on time would have led to irreversible ulnar nerve damage leading to permanent anaesthesia of her left hand and eventually clawing of fingers (deformity). Being a girl, this would mean double jeopardy (gender & disability). The early health seeking behaviour from the young girl and the timely intervention beginning from ANM to all levels of health care delivery is commendable. This enabled the young girl her prospects of getting married, and participation in all areas of family/social life.

Through the CDLCP project, RISDT 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) survey (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 3 to 5 persons who have skin pigmentation to the PHC for confirmation of leprosy every month. This is also confirmed by the community that we met. Approximately, 60-70% of the new cases to the PHC have been referred through the ASHA. A small proportion of the people come for confirmation directly to the PHC or connects with the ASHA if they have pigmentation. The ASHA lives in the same village; it works an advantage given her proximity to community and the possibilities of regular contacts with people to screen suspects. In one of the PHCs, one of the ANM shared on how she has given her mobile contacts to community members and they have been making mobile calls asking her to visit their homes as they themselves or their family members have patches.

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.

The discussion of 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 inputs from the Medical Officer or the Nodal person refresh their knowledge and clarify any doubts that they have from the field. Annually, the project staff members of RISDT carry out one-day session on prevention of impairment and disability and on how to make operational the program. 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. These screening activities are occurring at villages of all the ASHA we met, however, on any given month, she sees only 10 to 15 villages as part of the survey.

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 on 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 is also known to the community leaders and reported, 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 suspects identified by the ASHA at the field are referred to the PHC for further evaluation and confirmation. There is not fixed demarcated date for leprosy evaluation, most often than not, the suspects approach the PHC in the subsequent two or three days following the screening day. 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 through RISDT staff. It is only at one of the PHC that the Medical Officer had escalated ASHA's lack of incentives and assured the ASHA that they were going to be paid.

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. The loss to follow up across the PHCs visited ranges between 10 to 15% and this is accounted by migration. The reason for the low levels of drop is attributed to the intense follow up promoted by the project through survey and contacts through ASHA, ANM and project staff. An ASHA makes several visits to the house of the confirmed person and motivates him or her for treatment.

Screening of hidden cases through School Health Program

School health programs are conducted every month to cover all schools (mainly Government schools especially residential) 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 of the students by showing pictures of skin patches, and are asked to come forward for a physical examination. ANM/ASHAs and sometimes lady teacher help in examining the skin patch observed among girl students.

List of schools within each PHC area is available in 3 PHCs – Draksharama, Narsapuram and P. Geddada. 46, 27, and 28 schools are covered twice a year by the PHCs respectively. However, the details of the visit – date, number of students examined, and number of suspects/confirmed case are not available. It was told that their visit is recorded in the school register. The visit details are not captured in the Tablet, and the project staff members are not aware of the provision for recording such visits in the Tablet

The Government of Andhra Pradesh has launched a School Health Program Jawahar Bal Arogya Raksha (JBAR) across the state on 14 November 2010, under the name of Jawahar Bal Arogya Raksha (JBAR). As part of the scheme, Rajiv Vidya Mission (RVM) trains teachers to recognize students with health problems. The Women and Child department provides nutritious food to students suffering from malnutrition, and the Medical department provides treatment free of cost. Skin/patch examination is not part of the program objectives. However, it can be linked based on two of the program 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

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 is promoted by the project to reduce injuries. People are encouraged to moisturise the skin using coconut or other oils prior to carrying out the exercises of the hands and feet. RISDT has established 108 self-care groups where people meet to carry out self-care as a group; according to RISDT, 50% are functional, this however, could not be validated in the rapid evaluation process.

In the villages visited, almost all people who were interviewed were aware of the exercises that need to be carried out. Almost 75% were carrying out them out; however, it is difficult to ascertain if they are doing it on an everyday basis. What is important to note is that people in almost all the PHC areas we visited (except for one where the group had more number of burnt cases and of older age), those who did not have current ulcers had not got ulcers for the last 2 to three years. Among those who had ulcers (12), it was observed that the 7 people had wound was in remission. Only 5 people had florid ulcers and it can be inferred that the care of ulcers among those who were interviewed had received treatment.

People have been confidently carrying out ulcer self-care at their homes. The people reach out to the sub-centres to get bandage and gauze for dressing of ulcers. Except at one place where the respondents came from the same PHC area, none of them needed to travel to the PHC to get these supplies. 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 even; the reason given by them is that ANM do not have access to the medical equipment at the field level. On similar note, only two ASHA among the 37 met 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, probably 40% requiring self-care were carrying out self-care. However, most of the people carryout self-care sporadically; they do not practice it every day.

It is difficult to ascertain the functionality of the self-help group. Two self-care groups 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 come to a meeting point, they may not have the facilities to carry out self-care or may have other priorities that take priority over self-care. One of the groups was on microfinance and they met for loans matters that took priority.

2.3. Geographies in Leprosy

The project strategy is planned to reach people in the community and provide them services within the communities. What is noteworthy is that all people whom we met were living within the villages and nowhere did we observe that their houses were in a corner of a village or were made to stay separate from the main families. Our observation may be of a selective group; nevertheless, it is important given that the trends suggest that there is openness for people live in the mainstream. People did not express the desire to move into colonies or had made attempts to do so.

There was no leprosy colony in the coverage area of PHCs that were visited. The PHC MO informed that in the PHC areas where leprosy colony exists, the concerned PHC MO makes a monthly visit to treat general ailments they may have. During the visit, the DPMO accompanies the MO and distributes dressing materials and any other supplies they need.

2.4. Stigma and discrimination

Among the person we interacted, none of the persons expressed that they faced 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. Children with leprosy were attending school. 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. Having said this, it is premature to generalize that there is no stigma and discrimination in the

society and some presentation may be subtler and there is a possibility that it be accepted by the person as natural.

2.5. **Civic rights and social benefits**

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. However, the Antodaya[1] scheme was accessible to only 16 persons among the 58 people interviewed. People with leprosy were largely contributory with 66% involved in gainful employment or contributing to the family responsibilities. Those who were not financially independent through employment maintained themselves as functionally independent reducing their overall dependency on other members of the family. Some of those affected by leprosy contributed to non-productive household roles such as taking care of the children.

The Government intends to provide welfare services using the triad of Aadhar card, a bank account and the mobile. Among the persons interviewed, 66% had bank accounts and only 29% had access to mobile phones in their households. There is a possibility of several persons with leprosy stressed to access the welfare schemes in the absence of fulfilling the JAM trinity[2] strategy of the Government, a prerequisite for the direct transfer of the welfare schemes.

3. Provision of best practice tertiary care in the referral hospital

3.1. 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 RISDT / DLO / Medical College. Ulcer and RCS are commonly referred to the higher level. RISDT uses a format /referral slips to refer patients to PHC for further treatment. In Santhi Ashram PHC, a file for referral slips from RISDT was available. The link between forward and backward level is not seen. It is mostly one-way referral.

[1] *Antyodaya Anna Yojana scheme* provides food grains like rice and wheat at a subsidized rate for those who live below poverty lines. The scheme targets 5% of the population and intends to create an India that is hunger-free.

[2] An abbreviation for Jan Dhan Yojana, Aadhaar and Mobile. The government is pinning its hopes on these three modes of identification to deliver direct benefits to India's poor. Until now, the government has operated a multitude of subsidy schemes to ensure a minimum standard of living for the poor-MGNREGA, operated through the panchayats, which pays minimum wages to rural workers, ration supply of rice, wheat, pulses, cooking oil, sugar and kerosene at heavily subsidized prices through the PDS, supply of power, fertilizers and oil below market prices and so on. To reduce intermediaries that result in pilferage, leakages, corruption and inefficiencies, the government hopes that the JAM trinity can help. With Aadhaar helping in direct biometric identification of disadvantaged citizens and Jan Dhan bank accounts and mobile phones allowing direct transfers of funds into their accounts, it may be possible to cut out all the intermediaries.

Regarding referral for ulcer cases, Santhigram PHC has referred two ulcer patients, and other PHCs have not referred any in the last year. 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/MNOs were comfortable touching/holding the leg of leprosy patients while dressing. Stigma and discrimination is not detectable.

As per Disability Prevention and Medical Rehabilitation/DPMR policy and guidelines, care for simple ulcer should be available and provided by the PHC. But it is simply not practiced by some PHC. The quality and extent of care is also dependant on the leadership and the motivation level of the PHC staff.

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.

PHC referral and RISDT records correlate. Sample verification was done to confirm observations.

3.2. RISDT Referral Hospital

This is the only Tertiary Leprosy Referral Centre for East Godavari district providing outpatient, inpatient services for leprosy including ulcer care, MCR, RCS and Socio-Economic Rehabilitation. There is a full-time Medical Doctor who is also the Medical Director of RISDT and the Project Manager of CDLCP, East Godavari district. An experienced, visiting reconstructive surgeon does RCS for RISDT on a monthly, camp basis. The Physiotherapy unit has a trained Physio-technician and basic resources. Ulcer dressing is done by an experienced dresser. The inpatient wards are in the first floor, and there is a ramp to the first floor. However, the ramp is too steep for the wheelchair to navigate!

Detailed surgical physiotherapy assessment (pre & post-operative) is necessary for planning and follow-up, and mandatory 7 to 10 days' in-patient, pre-operative physiotherapy should be given prior to the RCS. The outcome of RCS in terms of cosmetic and functionality is 'fair,' however; it can be improved with better physiotherapy techniques.

Patient charts (paper) of all patients who visited RISDT with first and follow-up visits cannot be accessed. Since online HIS is not available with the Doctor during consultation, and is primarily used to enter data at the end of the visit, RISDT needs functional medical records department/MRD where all the patient charts are stored which can be systematically retrieved, documented and replaced.

In response, it was told that both physical and online are being maintained. Based on the physical records the online record was being entered. And if the physician requires, he could access it. The evaluator urges that routine assessment and its follow-up should be ensured and recorded.

3.3. Role of Medical College in Leprosy

Since the visit to the medical college was not feasible during the evaluation for lack of time, a tele-conversation with the health care staff linked to the medical college was planned. GSL Medical College, Rajanagaram in East Godavari district was chosen. The project staff arranged a telephone conversation with Mr. Chakadhar, APMO of Rajanagaram PHC who visits the medical college every Wednesday as part of his ATP. The dermatology department of the medical college holds weekly 'skin clinic' in which a 7-member team comprising Head of the Department of Vizag Medical College, Assistant Professors of GSL, and other Post Graduates dermatology students give consultation. This clinic has been in place since 2016 and the DLO has deputed one APMO to facilitate the clinic. It is organized on the first Wednesday of every month from 9am to 4 pm. 30 to 40 patient referrals from Rajanagaram mandal and Kakinada area visit the monthly clinic. New cases are detected at the rate of 4 to 5 cases every month. Reaction and neuritis are diagnosed and referred back to the concerned PHC for further treatment through the APMO. Complicated cases are managed by the Medical College including admission and further referral as needed. No reconstructive surgery is being carried out through the medical college, and identified persons are referred to RISDT.

4. Providing technical support in terms of capacity building and monitoring for the Program

4.1. Training

4.1.1. Medical Officer

Four MOs have received one/two days training in leprosy given by the DLO office at the beginning of their career in the last two years. MO in Draksharama got leprosy training in 2006-07. Narsapuram MO had no training in leprosy (joined in August last year). Training status of P. Geddada MO was not known, as she was not available during the visit.

4.1.2. DPMO/APMO

The 2 of 3 APMO/DPMOs have completed 6-month Para Medical Worker/PMW course in leprosy long back (80s), and one has received Non-Medical Assistant/NMA training in leprosy. No refresher training was given after that.

4.1.3. ASHA/ANM

ASHAs and ANM are given (2 to 3 hour) orientation in leprosy during the monthly review meeting of ASHA (ASHA day) by the DPMO/DC.

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.

4.2. **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-centre is being supervised regularly. ASHA is not supervised, as she is not a health care staff but a volunteer. ATPs of supervisors are approved by the PHC MO on a monthly basis. APMO submits the ATP to the DPMO. There is no monitoring and supervision checklist of tasks available of what needs to 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 centre 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.

4.3. 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. Rarely does the joint visit get carried to low prevalence pockets or for the purpose of only monitoring field operations.

4.4. Digitalization of data

RISDT 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 not getting loaded as new information was being added. There are concerns from the community as getting consents for photograph was not possible in some of the new cases, those newly married or were children and youth. Some of the people were migrating to other places too. The total estimation by the NGO whose data could not be added could be to the tune of 15%. The project has completed updation for the divisional coordinators who hold functional tablets and

there are two of them who have problems in their tablets and hence there is a backlog in data entry.

5. Management capacity of the partner

5.1. Human resource as capital

The project has appointed 7 Divisional Coordinators (initially 5) reporting to the Project Coordinator who in turn reports to the Medical Superintendent. The project team has been long standing and has gained experience over the years on leprosy in the current project or in the earlier positions within leprosy projects. Two each have expertise in the DISPEL and POID projects, one is a physiotherapist, one from government leprosy program and two from public health programs. The blend has enriched the intervention with the capacities that each of them brought to the pool. The team draws on additional support for RCS through the hospital staff members.

The project team is moderately well informed on and have clarity on the articulated project aim, objectives and activities of the current project. The team actions were greatly goal directed and it was reflected in the connectedness they experienced with the community and their issues at the field points and with the PHC team. The teams had a weekly plan for visits which governs their focus for the visiting the PHC and villages. During their visit to the PHC, the project staff members conduct training for the PHC and/or ASHA.

The Medical Superintendent and the Chairman are well informed on the activities at the field. The Medical Superintendent makes weekly visits to the field sites and is on board with the realities. It was reflected in the additional efforts taken at the high epidemic spots.

5.2. Effectiveness

Particular	2014	2015	2016	2017	Total
New cases NFA done	419	360	399	181	1359
Deformity cases NFA done	562	976	1081	624	3243

The 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 District 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. The District Leprosy Unit, in the context of diminishing manpower resources within their

program, consider and take support from the NGO with the consideration that they are additional hands available at their disposal.

The Government system finds the NGO effective in their functions and jointly, they have been able to address and strengthen the leprosy care (60%). The District Leprosy Unit values these inputs of the NGO inputs that have contributed to the prevention of impairment and disability through their support in early identification and initiating treatment through counseling, 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, the provision of disability certification and the incentives for the ASHA were areas that the project was not been able to assure that the ASHAs get their incentives for the work they have done. 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, these have taken a backseat, the reason being that the team did not have the competence to develop them and there was no budgetary allocation. 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 RISDT is one of mutual comfort and respect. There have 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.

5.3. Efficiency

The program has been 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 not seen among the newly identified persons with leprosy met or noted in the records of the PHC. This can be attributed to 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 have 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.

5.4. Sustainability

The intervention is largely owned by the system; the ASHA and the ANM have been identifying the suspects and bringing them for confirmation to the PHC and the District Leprosy Unit is driving is engaging with the PHC system to continue the activities as part of routine PHC work. 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 through incentivizing the ASHA, streamlines the supplies of MCR, drugs and self-care supplies and promotes self-care as an important part of the intervention the momentum cannot be sustained.

Nevertheless, the challenge for the District Leprosy unit is the shrinking leprosy workers due to the Central Leprosy Program strategy to mainstream leprosy within the General Health System. The program is new and the presence of Leprosy Nodal Workers is not fully functional. Added to this, is the frequent transitions and transfers of the District Leprosy Team and the PHC personnel that brings within the need for regular training, motivation and quality assurance within the government health system, which is a challenge for the stretched system.

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.

The ASHA, the NLEP nodal persons at the PHC, the Medical Officer at the PHC and the District NLEP team have district team that collaboratively worked to confirm the suspects, carry out the nerve function test and confirm and treat the new suspects at the PHC and if needed refer those which require additional care to the referral centre. Those complicated cases that require reconstructive surgery was routed through the District Nucleus Team and once reviewed and ascertained that they require RCS are referred to the referral centre.

The community is central to the process and their engagement is essential to drive the results. The ASHA at the village level is the entry and she has with a great zeal and effort carried out the survey and contacts in the absence of incentives.

The theory of change is conceptualised on a firm ground, however, there have been some issues that need to be considered. To build capacity of the general health systems, it is essential that the team periodically update knowledge through regular in-house sessions and through trainings from experts. While the backstop mechanism is in place and adds to knowledge and skill building, the change needs to be monitored through the action taken reports, field visits of the management team of both RISDT and the Swiss Emmaus India.

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 intermediatory 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 is the most effective mechanism that 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 proposed has been 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.

Interpretation, Conclusion & Recommendations

I. Proposed Next Phase

The rapport built up by the RISDT 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 RISDT namely DISPEL/POID Pilot and the current CDLCP project.

The proposed next phase is crucial and it should be the beginning of 'weaning off' phase where a proportion of PHC/Health Facilities (perhaps 30%) are weaned off support from RISDT, but are given strategic support which includes monitoring for performance and quality. 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 program 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 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

The next phase of the project with a clear exit strategy has been recommended.

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.

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.

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.

Skilling ASHA on survey for complete reach with additionally responding to softer issues such as anesthesia needs to be promoted.

II. Role of CDLCP

CDLCP project has played a crucial role in bringing the mindset 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. Currently, the POID activities are being carried out 'jointly' by the District Coordinators and the DPMO/APMO. 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 aim for moving away from doing the work 'jointly' to make the PHC staff 'do' and support them as necessary. This strategy should be conveyed clearly to the NLEP staff from top-down. Similarly, the project staff should be empowered to play that right role clearly, and with good capacity. It is to know when, what and how much to do by the project staff. They should not be doing the DPMOs work, and the DPMOs should be aware of the DCs role clearly communicated to them by the DLO office. In this regard, the role of project/program manager through planned monitoring of field activities is crucial.

Recommendations

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.

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 the monitoring and supervision mechanism of the project. The ASHA being a central force within the system for identification, her incentives need to be addressed on priority. This should also bring about greater expectations and streamlining of outreach activities to the fullest.

III. Ulcer Care

In leprosy/POID program, 'ulcer care' is a major component and a major burden to the health care system, which is often neglected by the PHC staff, and therefore gets referred to RISDT or to the district hospital. One of the reasons for neglect could be that, there are many components in POID to focus starting from nerve function assessment, reaction & neuritis, follow-up of Steroids, reconstructive surgery, contact tracing, provision of MCR footwear, school health program etc. Needless to say, all of these are integral and important. However, it should be noted that the focus on the most important component, which is ulcer care many a times, gets the least attention.

The evaluation findings show good availability of general health care staff – 5 ASHA; 2 ANM/HA & 1 MPHS for every 1000 to 5000 population. The treatment of ulcers is carried out by the person or by

the PHC staff. When the person does himself/herself, s/he needs to collect the supplies from the PHC or the sub-centre.

People we visited at the PHC and in the community have been getting their bandage and gauze for dressing of ulcers at the PHC. Except at one place where the respondents came from the same PHC area, none of them needed to travel to the Pidathamamidi Primary Health Centre to get these supplies.

Among the people met, those who did not have ulcers, their last ulcer was two to three years back. While it is difficult to attribute it totally to the project given the multiple inputs, it can be affirmatively said that it was contributed by the intensive intervention provided by the project.

And most importantly, it was observed that this group of staff members has no apprehension (stigma or discrimination) in touching/dressing ulcer. Taking into consideration that a maximum of 5 persons needing long-term care/ulcer are living in this population set, it can be effectively and efficiently managed both in terms of ulcer prevention and its worsening at the community level with a single SMART objective/outcome of "all simple ulcers are identified and managed at the village level." This can be undertaken as a worthwhile programmatic or interventional research to study its effectiveness. ASHAs could be trained in supervising self-care at village level for effective healing of ulcers.

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, 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.

Recommendations

A programmatic or interventional research focusing on "ulcer care" through the general health care system may be considered.

Operations research could be conducted on spots where is there is high PR to identify the reasons for the same and to develop an effective strategy to respond to repeat infections in the same geography.

Project or through NLEP should provide training for ANMs and MNO in RISDT or other tertiary centers. Basic resources required for dressing should be made available in all PHC.

The project could consider setting up Leprosy Rehabilitation Centers (LRC) within the Government institutions which could support the process of transition.

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

Specific points in documentation:

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. Further, guidelines states that NFA should be done for all patients and the follow-up, but it doesn't specify who should do it. In the evaluator's opinion, MO should know how to do NFA, read and make clinical decision based on the assessment. The nodal person/APMO/DPMO should be confident in performing NFA and recording.

Referral process (two-way) should be documented in the referral register.

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.

Patient charts of last 5 years should be kept in the PHC medical records/nodal person.

MCR indent and distribution process needs to be systematic carried out with appropriate documentation of processes.

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. One-off training will not be sufficient, and more on-job trainings linked to their role should be planned.

Recommendations

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 for Medical Officers, field training in diagnosis and reaction & neuritis should be given by the project manager.

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It is good that school health programs are being carried out through state-wide JBAR (*Jawahar Bal Arogya Rakshak*) program. However, there is no section to cover skin/patch examination. CDLCP/NLEP staff members 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 programs for early identification and disability prevention and for sustainability.

Recommendation

Program advocacy at the state level to incorporate skin/patch examination through state-sponsored school health program/JBAR is recommended based on the success of identifying children with leprosy as a part of the CDLCP project!

VIII. Monitoring & Supervision

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

Recommendations

A simplified monitoring & supervision checklist for PHC and SC should be developed for NLEP, and it should be submitted by the supervisory staff along with the ATP compliance.

A similar checklist should be followed up as part of project monitoring and reporting.

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The referral Centre is functioning well with a full-time Medical Doctor/Director 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 in-patients including 'resting' ulcer.

Recommendation

The Physiotherapist need 'intensive' training in RCS and the physiotherapy protocol should be strictly followed - detailed assessment, one week to 10-days pre-operative physiotherapy cannot be compromised.

Patients with recurrent ulcer admitted two or more times in a year should be identified and a targeted approach in terms of counseling, 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 in delivering leprosy services. However, there are few limitations as OBA is 'output-based' and not 'outcome-based,' and is not linked to performance, quality, and efficiency parameters/indicators. The concept of health financing and its learning recommends 'strategic purchasing' rather than 'passive purchasing' of health services.

This is debatable, and Fair Med can take a decision according to the needs of the organisation.

> A **strategic** purchaser allocates funds in a way which actively promotes improvements in service quality and efficiency, through the use of incentives and administrative mechanisms. An example of this is paying hospitals based on the number of patients successfully treated, following a review to ensure that the services provided were appropriate.
>
> This means allocating funds based on the following type of information:
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> - which services should be delivered as a priority, based on a health needs assessment of the population
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> - Protects funding for primary healthcare services
> - Pays relatively high amounts for primary health care (PHC) services in order to reflect their priority
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> *Source: Health Financing Policy for Universal Health Coverage, WHO, 2016*

Recommendation

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 programs in the country. Being a national ILEP Coordinator, FAIRMED may consider advocating, initiating and developing a national policy on this.

XI. 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. The evaluation findings did capture the glimpses of the tangible change like timely detection of 'high-risk' elbow patch by the ANM/ASHA that has saved a young girl from irreversible, life-long disability. 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.' Recognizing the staff members (in this case the ANM/ASHA) who have done a commendable job should be part of the annual, anti-leprosy day celebrations.

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

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.

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.

Anti-leprosy day should also recognize the commendable job done by general health care staff in leprosy, which would serve as a role-model for others.

General Health System as a point of first contact

The project has been successful to make the General Health System as the first point of contact. People are reaching out to PHCs and subcentre for treatment services and for self-care supplies on their own without dependence on project team. The ASHA in the village is fairly well known among the people we met and it is apparent that she has been making her contacts at the village level. This is commendable in a context where ASHA are not paid for

Interpretation, Conclusion & Recommendations

I. Proposed Next Phase

The rapport built up by the RISDT 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 RISDT namely DISPEL/POID Pilot and the current CDLCP project. Currently, the 'working together' is happening, and now it is time to work with an effective 'exit' strategy

The proposed next phase is crucial and it should be the beginning of 'weaning off' phase where a proportion of PHC/Health Facilities (perhaps 30%) are weaned off support from RISDT, but are given strategic support which includes monitoring for performance and quality. 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. The missing link is the intermediate services with the Government system and that leads to referrals to the tertiary centre. It might be an opportunity to establish secondary level service provider as a part of the next phase of the CDLCP project thereby further strengthening the public health system (PHS) to manage ulcers, disability and treatment within general health system. This would necessitate a combination of weaning out with need based support at the primary level, and establishing the secondary level care, and ensuring strong referrals between primary, secondary and tertiary level care could be an option worth discussing! What do you think?

Since the number of vertical staff (NLEP) staff within the general health care system is shrinking with staff retiring and not being replaced, the state strategy of having a nodal person for leprosy activities in the PHC where there is 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 clear exit strategy has been recommended.
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.

II. Role of CDLCP

CDLCP project has played a crucial role in bringing the mindset 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. Currently, the POID activities are being carried out ‘jointly’ by the District Coordinators and the DPMO/APMO. 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 aim for moving away from doing the work ‘jointly’ to make the PHC staff ‘do’ and support them as necessary. This strategy should be conveyed clearly to the NLEP staff from top-down. Similarly, the project staff should be empowered to play that right role clearly, and with good capacity, as the

capacity of project staff is not adequate enough to bring in the change. The role of project/programme manager through planned monitoring of field activities is crucial.

Recommendations

1. 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.
2. 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 the monitoring and supervision mechanism of the project.

III. Ulcer Care

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, and therefore gets referred to RISDT or to the district hospital. One of the reasons for neglect could be that, there are many components in POID to focus starting from nerve function assessment, reaction & neuritis, follow-up of Steroids, reconstructive surgery, contact tracing, provision of MCR footwear, school health programme etc. Needless to say, all of these are integral and important. However, it should be noted that the focus on the most important component, which is ulcer care many a times, gets the least attention. The evaluation findings show good availability of general health care staff – 5 ASHA; 2 ANM/HA & 1 MPHS for every 1000 to 5000 population. And most importantly, it was observed that this group of staff members have no apprehension (stigma or discrimination) in touching/dressing ulcer. Taking into consideration that a maximum of 5 persons needing long-term care/ulcer are living in this population set, it can be effectively and efficiently managed both in terms of ulcer prevention and its worsening at the community level with a single SMART objective/outcome of "all simple ulcers are identified and managed at the village level." This can be undertaken as a worthwhile programmatic or interventional research to study its effectiveness.

In response to this conclusion, it was told that ulcer care is a routine treatment for the PHCs and the MO is capacitated in doing through his/her training. Swiss Emauss India was keen that at least if all simple ulcers are being managed at the PHC then it's a huge success. May be for complicated and severe ulcers people can then be referred to the secondary level as and when it's established in the following phase and the rest to the tertiary levels. This form of referrals could be really beneficial & effective.

The evaluator agreed that not all people will require all POID services, and the different component of POID services are divided across the 3 levels of health service delivery. This has to be established where it is not available e.g. in LRC or FRC, and strengthened where it is available e.g. PHC and the tertiary levels.

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, 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.

Recommendations

1. A programmatic or interventional research focusing on “ulcer care” through the general health care system may be considered.
2. Project or through NLEP should provide training for ANMs and MNO in RISDT or other tertiary centres. Basic resources required for dressing should be made available in all PHC.

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.

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1. Specific points in documentation:
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In the context of GoI/CLD initiated the leprosy case detection campaign (LCDC) as a priority activity with an aim to diagnose and treat early cases of leprosy. And, FM and its partners were keen on establishing a secondary level service provider as a part of the CDLCP project thereby further strengthening the public health system (PHS). Therefore, a combination of weaning out with need based support at the primary level, and establishing the secondary level care, and ensuring strong referral's between primary, secondary and tertiary level care can be a potential option/way forward.

Recommendation

2. First Referral Unit/FRU should be identified and strengthened with 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.

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4. The Physiotherapist need 'intensive' training in RCS and the physiotherapy protocol should be strictly followed - detailed assessment, one week to 10 days pre-operative physiotherapy cannot be compromised.
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X. Output Based Activity

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5. Anti-leprosy day should also recognize the commendable job done by general health care staff in leprosy, which would serve as a role-model for others.

Annexure

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).
    - 10.1. Are you satisfied with the way the project is being managed, in terms of –
    - 10.2. Your team members, the way you work as a team to achieve results
    - 10.3. nature of engagement with government systems and frequency
    - 10.4. project management arrangements between FAIRMED and CDLCP
    - 10.5. relationship and working arrangements with government and other non-government stakeholder (only for PM/PD and NGO Advisory team)

Impact

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

Sustainability

12. 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 functionaries reconstructive surgery etc.), BCC efforts, etc?) at the end of the project?
13. What are some of the factors that can influence sustainability of these interventions?
14. 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.
    - 14.1. Hospital and Government Medical and non-medical staff at the health facilities
    - 14.2. The focus of these questions will be to understand the perspective and experience of the hospital / health post staff of CDLCP interventions.

Relevance

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

Effectiveness

20. 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)
    - 20.1. Development of customised standards/l protocols for standardised care
    - 20.2. Training and capacity building project for health post staff
    - 20.3. Innovative practices for furthering the prevention of impairment and disability
21. Do you feel that you have benefited from the capacity building provided by the project?
22. What are the actions that you do to prevent impairment and disability in people with leprosy?
23. 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?
24. Are you aware of the referral slip introduced by CDLCP? Have you begun using it? What is your opinion regarding its usefulness?
25. 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

26. How would you describe the quality of care and service delivery provided at your health facility and the quality / frequency of referral?
27. 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?
28. In your opinion which of CDLCPs interventions have worked well or not?
29. Do you have any recommendations to improve the services provided by CDLCP?

Sustainability

30. Will any of these new systems (self-care/ referrals / community outreach) and improvements that have come in after CDLCPs work be sustained without CDLCP?
31. 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.

1.1. What is the purpose of your visit today to this health centre? Were you able to get the required services?

1.2. 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?
1.3. 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?
1.4. How many times were you visited by the ASHA or any other government outreach worker? Do you feel these visits were adequate?
  1.4.1. 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?
  1.4.2. How many times were you visited by the CDLCP staff member? Do you feel these visits were adequate?
  1.4.3. What activities organized by government and CDLCP in your community have you attended? What were your experience / learning in those activities?
1.5. Do you have any recommendations for the services provided by
  1.5.1. health centre
  1.5.2. 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 has 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?	

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

Two focus group discussions with men and women patients admitted in RISDT. 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.

Women FGD - 7 participants.
Men FGD – 6 participants

Discussion questions/points:

1. How did they know about RISDT?

Through PHC Referral – 12; voluntary reporting – 2

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

Seven of them have been admitted twice for ulcer care in the last year. Time gap ranges from 3 months to 1 year. Three persons were there 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 anesthesia as a pre-disposing cause for ulcer. All are aware of self-care process.

6. How satisfied are you with RISDT services?

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

7. What are your suggestions for improvement?

“No suggestions. Please continue the same!”

List of respondents

RISDT

1. Nageshwar Rao, Divisional Coordinator
2. David, Divisional Coordinator
3. Ramachandra Rao, Divisional Coordinator
4. Veerababu, Divisional Coordinator
5. Martin Luther, Divisional Coordinator
6. Prasad, Divisional Coordinator
7. Praveen, Coordinator
8. Dr. J. P. Palla, Medical Superintendent
9. Slessler Babu, Chairman

Swiss Emmaus India

10. Bijoy Swain

NLEP staff

11. Gopalkrisna, DPMO
12. Rajmanjula, HEO
13. Johnbabu, DPMO
14. Dr. Raghavendra, DNMO
15. S Krishna Rao, DMO
16. K. Srinivas Rao, NLEP-in-Charge

PHC staff

17. G.V. Krishna Kumari, MPH
18. T. Hymeshah, MPH
19. P. Venkatalaxmi, MPHA
20. A.G Prameela, MPHA
21. P. Gangadurga Bhavani, MPHA, PHC Pidathamamidi
22. Tulsi, ANM, PHC Pidathamamidi
23. Shantahram, ANM, PHC Pidathamamidi
24. B. R. Ramachandra, MPH, PHC Pidathamamidi
25. K. Lakshmi, MPHW, PHC Pidathamamidi
26. K. Ammulu, MPHW, PHC Pidathamamidi
27. K. V. Narohayamma, MPHW, PHC Pidathamamidi
28. Dhana Lakshmi, MPHW, PHC Pidathamamidi
29. Dr, Indrushree, Medical Officer, PHC Pidathamamidi
30. Dr. Chandrakiran Babu, Kulampudi PHC, Kulumpudi
31. Dr. G. L. Gayatri, Medical Officer, PHC Angara
32. P. Suresh, MPHS Male, PHC Angara
33. N. Anantha, II ANM, PHC Angara
34. G. V. Venkata Laxmi, MPHA Female, PHC Angara
35. G. Venkatalaxmi, II ANM, PHC Angara

36. G. Kumari, MPHA, Female, Simbadripuram
37. T. Venkata Laxmi, MPHA, Female, Chillangi
38. V. S. L. Kumari, MPHA, Female, J.P. Nagaladri
39. P. Lova Kumari, MPHA, Female II, Chillangi
40. D. V. S. S. Narayangamma MPHA Female II, Simbodripuram
41. K. Delli, MPHA, Female II, Kinlaibhadi
42. B. Naga Raju, MPHA, Male, Chillangi
43. K. Vijaylaxmi, HEO, KPD
44. P. Santhikumari, PHN, KPD
45. V. Baby, Staff Nurse, KPD
46. V. James, MPHA, Male, KPD
47. N.V.V. Narayaa Roa, MNO, KPD
48. M. Ganga Raju, APMO, KPD
49. 3 ANMs at Biccauvulu PHC
50. 6 ANM at Peddapalem PHC
51. 10 ANMs at Rachapalli PHC
52. 10 ANMs at Peddapuram PHC
53. 10 ANMs at Rachapalli PHC
54. 10 ANMs at Draksharama PHC
55. 3 ANMs at Kuttukuluru PHC
56. 11 ANMs at Narsapuram PHC
57. 1 PHN at Narsapuram PHC
58. 1 CHO at Narsapuram PHC
59. 9 ANMs at Ramapachovarma PHC
60. 3 Health Assistant Male at Peddipalem

ASHA

61. A. Laxmi, ASHA, Kirlampudi PHC
62. B. Rama, ASHA, Kirlampudi PHC
63. D. Uma Rani, ASHA, Kirlampudi PHC
64. P. Rama Laxmi, ASHA, Kirlampudi PHC
65. D. Ramananna, ASHA, Kirlampudi PHC
66. M. Ammani, ASHA, Kirlampudi PHC
67. D.J.S. Mani, ASHA, Kirlampudi PHC
68. M. Ananda Kumari, ASHA, ASHA, Kirlampudi PHC
69. M. Jyothi, ASHA, Kirlampudi PHC
70. D. Parvathi, ASHA, Kirlampudi PHC
71. M. Veeralaxmi, ASHA, Kirlampudi PHC
72. 5 ASHAs, Biccaovulu PHC
73. 3 ASHAs at Peddipatem PHC
74. 7 ASHA at Rachapalli
75. 12 ASHA at Draksharama
76. 5 ASHA at Kuttukuluru PHC
77. Ch. Gangabhavani, ASHA, PHC Angara
78. K. Mary Vijaya Kumari, ASHA, PHC Angara
79. J. V. Raghavelu, ASHA, PHC Angara

80. K. Laxmi, ASHA, PHC Angara
81. P. Venkata laxmi, ASHA, PHC Angara
82. S. Sarala, ASHA, PHC Angara
83. T. Sridevi, ASHA, PHC Angara

Other services

84. Dr. Prasanna, Santhi Ashram
85. Mr. K.V. Prasad (PMO), Shanthi Ashram

Service users

86. Saribolabblu, 55, Male
87. Marmedichakra Raoa, 75, Male
88. Sada Srinivas Rao, 35, Male
89. Ande Laxman Rao, 92, Male
90. Bore Yesu, 55, Male
91. Chantapalli Ganaya, 60, Male
92. Vangaku Veeraiah, 65, Male
93. Kutipudi Sundaram, 50, Male
94. Atla Rajampudi, 50, Male
95. Yendapallimalla Rao, 60, Male
96. G. Arjunudu,42, Male
97. Koasthali Raghavav, 60, Female, PHC Kirlampudi
98. Buddo Appa Rao, 49, Male, PHC Kirlampudi
99. Domerlas Srihari, 76, Male, PHC Kirlampudi
100. Pennaganti Suri Bahu, 60, Male, PHC Kirlampudi
101. Vaitturi Muralliayya, 75, Male, PHC Kirlampudi
102. Pentakota Surya Rao, 70, Male, PHC Kirlampudi
103. Gotteti Nooka Raju, 39, Male, PHC Kirlampudi
104. Akula, Venkamma, 60, Male, PHC Kirlampudi
105. Kunjan Sakkubhai, 60, Female, PHC Pidathamamidi
106. Kosu Nagarajamma, 55, Female, PHC Pidathamamidi
107. Chodi Ammaji, 55, Female, PHC Pidathamamidi
108. Pathar Venkateshwaralu, 50, Male, PHC Pidathamamidi
109. Thurram Chukkanna Dora, 28, Male, PHC Pidathamamidi
110. Valluri Bhavani, 35, Female, PHC Pidathamamidi
111. Mobiriparmu John, 55, Male, PHC Gangavaram
112. Mobiriparmu Chakravarthi, 21, Male, PHC Gangavaram
113. Kunjani Chellamma Dorai, 50, male, PHC Gangavaram
114. Chavalam Venkayamma, 48, Female, PHC Gangavaram
115. Chavalam Venkatalakshmi, 38, Female, PHC Gangavaram
116. Karem Rajamma Dhar, 58, Male, PHC Gangavaram
117. 7 people at Biccaovulu PHC
118. 4 people at Draksharama PHC
119. 7 people at Kuttukuluru PHC
120. 1 Person at Narsapuram PHC