Global Partnership for Zero Leprosy

Best Practice: *Promotion of Accessibility of Services for Persons in Need in the Prevention of Impairment and Disability (POID) due to Leprosy in Guntur and East Godavari Districts of Andhra Pradesh State, India*

Subthemes
- Early detection and prompt treatment
- Disability prevention and treatment
  - Secondary prevention

Target Audience(s)
- Program managers
- Health staff
- Persons affected by leprosy
- Donors
- Other partners such as NTD NGOs

Contributors
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Key Messages
This project focuses on prevention activities at the primary and tertiary levels, with an aim to diagnose early and treat people. The project was implemented in collaboration with the local government public health system and Swiss Emmaus India with a belief in strengthening the prevailing health system.

Key Informant / Date Submitted
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Description of the Best Practice

Introduction
The post-leprosy elimination period in India observed an under-prepared general health care system accepting leprosy into the mainstream service-delivery system. With a shift from a well-supported, high priority specialized program to one integrated with the General Health Services (GHS), leprosy elimination faced problems of sustainability. After elimination of leprosy as a public health problem, other health priorities tend to become relatively more important for national health administrations with reduction in focus and funds for leprosy control.

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The problems that need to be addressed include
- Providing technical support for referral and support services in leprosy management
- Managing lepra reactions and other complications
- Teaching and training of health service staff about leprosy detection, treatment, and the referral system for more efficient management at the peripheral level

The extent of the problem on the population can be captured as follows:
- A delay in early identification leads to deformity
- The needs of the patients are not considered and fulfilled by GHS
- The absence/lack of prevention of impairment and disability (POID) services in the peripheral health centers leads to increased burden of leprosy on the population
- Lack of self-care material/supplies further worsens the deformity and adds to the woes of the people
- Incapacitated health care staff were unable to provide quality services

Primarily, the POID project contributed to Pillar II of the WHO *Global Leprosy Strategy 2016–2020,* "stop leprosy and its complications." However, this project further adds value to Pillar I, "strengthening government ownership, coordination and partnership," thus finally contributing to Pillar III, "stop discrimination and promote inclusion."

Objectives and Methodology

Main goal: The quality of life of leprosy affected persons is improved

Objectives
- To improve POID services in the primary health care system
- To provide POID services at the tertiary care referral hospital
- To strengthen POID services at the community level
- To develop a project management system for effective implementation of the project

The methodology used were
- Strengthening the existing public health care delivery system for detection of new cases of leprosy as well as detecting reaction and neuritis cases before development of any deformity
- Generating community-level participation and strengthening home-based care for rationalization of tertiary care
- Provision of best practice tertiary care in the referral hospital
- Providing technical support in terms of capacity building and monitoring for the program

The design of the POID project has been based upon lessons learned from previous projects, including DISPEL (Disability Prevention and Education in Leprosy) launched between 2001–2009 and AP-POID from 2010–2013 in two high endemic districts of Andhra Pradesh. However, since then, FAIRMED sent

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their Indian Technical Coordinator to Nepal to study some best practices model at Lalgadh Leprosy Hospital, and it was thought that a strategy shift from the present service delivery model to a community-based prevention model would be helpful.

The lessons learned during the planning stage of this new project are that early detection of new/hidden cases of leprosy along with ensuring complete treatment, timely identification of cases with reaction/neuritis, and prompt management hold the key to POID in leprosy cases. Therefore, the proposed project will address these issues to further strengthen the primary level care.

Implementation of Practice

Main activities
- Refresher training was provided to the identified staff responsible for NLEP at the primary health center (PHC) level
- Auxiliary nurse midwives (ANMs) and Accredited Social Health Activist (ASHAs) were involved to help promote suspect case identification and referral and provision of ulcer care at the community
- Availability of medical supplies was ensured through advocacy
- Line listing of the patients through android-based application was initiated, with importance of follow up of both the old and new cases
- Joint monitoring of the program was carried out in collaboration with the district NLEP staff
- District- and state-level steering committees were formed to monitor the progress of the project

The trainings were mainly carried out collaboratively at the PHCs using the existing health budget. However, during the monitoring visits, the experts could pass on the on-job skill building to different cadres of health care workers at the PHC and sub-centre levels. The materials for the training and awareness were jointly developed by the implementing NGO partner and district health society in consultation with each other and utilizing respective resources.

The advocacy and community engagement programs undertaken during this phase were jointly carried out. The project worked on advocating for inclusion and stigma reduction through the existing women self-help groups (SHGs) and other community-based organisations (CBOs) in the project areas.

Were persons affected by leprosy participating in the design and practice itself?
Yes, organisations such as the Association of People Affected by Leprosy (APAL) and Society of Leprosy Affected Person (SLAP) participated in designing the program and practicing it at their level. Self-care groups would meet at the PHC on a stipulated day to practice the self-care and discuss various issues with the health care staff. The SHGs themselves take appropriate actions if there is any discrimination in the community.

Key implementers and collaborators were
- People affected by leprosy

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- The state and district NLEP staffs
- RISDT and GRETNALTES (both FAIRMED-supported, local NGOs)
- FAIRMED INDIA

The resources utilized were from government and FAIRMED sources. FAIRMED supported the human-resource costs, including travel, administrative, and a few training components, whereas the government supported the costs of trainings, medical supplies, and advocacy components. The overall expenses of the tertiary care hospitals were entirely supported by FAIRMED India.

Results—Outputs and Outcomes

Key results
- A capacitated GHC staff ensures quality POID services at the PHCs through
  - Early identification and referral to the PHC for diagnosis and treatment
  - Improved documentation of people receiving services
  - Availability of other services, including counseling, multidrug therapy (MDT), steroids, micro-cellular rubber (MCR), self-care kits, referral, etc., at the service delivery centres

- Access of POID services at community level
  - Elderly and immobile people were provided services at their doorsteps
  - It is worth noting that various government social schemes were provided to the people affected by leprosy
  - Active involvement of people in improving self-care was the highlight of the project
  - Regular supply of self-care materials was a key aspect of the project

Were data management processes of the best practice consistent and transparent to draw conclusions?
Data management through the Hospital Information System (HIS) at the project head office and data collection through android-based technology (TIS-Tablet Information System) complement each other. In addition to these two systems, the regular reporting systems, back-stopping exercises, mid-term evaluation, as well as end evaluation all contributed to the conclusion of best practice.

Was an assessment of the practice carried out?
Yes, a mid-term evaluation and as well as an end evaluation have been carried out for the whole project (see **Further Readings** below). The outcomes from the evaluation were also widely disseminated with various stakeholders.

Is the project completed or are some results still to be expected?
The project was to have completed its tenure in December 2018 but has been extended until August 2019 with an exit plan.

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Lessons Learned

What worked really well?
- The involvement of primary care health staff including the outreach staff (ANMs, multi-purpose workers, and ASHAs) in delivering the services has been highly motivating and encouraging
- The people practicing self-care at home are highly praiseworthy and the support they received from their families has been enhanced
- People receiving social security benefits are one of the key achievements of the project

Services have been provided to people over the last four decades, helping build a rapport with the community. However, the project has further strengthened the bond by the constant efforts of the Divisional Coordinators who have championed the change.

What did not work?
There is a gap in early identification due to the migration issue. Although stigma has been reduced, it cannot be generalized. Shortage of government funds for refresher trainings to health care staff is a challenge. Irregularity in releasing the incentives to ASHA and in the supply of MCR by the government are still areas of concern.

Replicability and Scalability

Has the practice been implemented in more than one setting?
Yes, the project has been implemented in two districts of Andhra Pradesh and two districts of Maharashtra State in India.

What long term effects can be achieved if the practice is sustained over time?
- The program could be largely owned by GHS, ensuring greater probability of sustainability
- A facilitative and non-discriminatory relationship between the community and health system staff could be established, making services more likely to be sustained

What are the requirements to sustain the practice over time considering contextual factors, institutional support, human resources?
- Regular capacity-building program for both the community and the general health care staff
- Efforts to facilitate and ensure community participation
- Good rapport via dialogue between the service providers and receivers
- Regular monitoring and supervision
- Continual support by external agencies

Conclusions
This project has been highly beneficial to people, as disability prevention and management has been the centerpiece of this project. Early diagnosis has been the focus, with prevention of disability as a central

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theme of this project. The success is contingent on sustaining the gains from the project with dynamic synergy between both the person and the health system.

The involvement of the government health system in preventing, treating, and managing disability with complementary efforts of the person/community has been the hallmark of this project.

Active engagement of the government health systems and the community is paramount to extend this good practice in other endemic areas, as it significantly contributes towards self-sustenance.

Further Readings

The following secondary materials are available along with the Best Practice at http://zeroleprosy.org/toolkit/.

Mid-term Report:
1. Project for the Prevention of Impairment and Disability in Guntur and East Godavari Districts of Andhra Pradesh, End Evaluation Report, March 2014.

End Evaluations:
2. CDLCP End Evaluation: RIDST Report (East Godavari), 2017
3. End of Evaluation of CDLCP Project: GRETNALTES (Guntur), July 2017

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