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Case study - Lepra

Adaptive programming in "reaching the unreached"

Lepra is a UK Aid Direct grant holder, and with this project they have focused on the empowerment of women to prevent disability due to leprosy and lymphatic filariasis in rural Bangladesh.

The project was designed using relatively good leprosy data, but with many unknowns regarding lymphatic filariasis (LF).

A 2014 situation analysis and disease mapping for leprosy, provided up-to-date information as a baseline for the design (especially when it came to indicator targets.) In addition, the team benefited from having staff with many years of experience in the leprosy sector.

Previous projects showed that actively seeking leprosy cases was effective in increasing early detection and lowering the risk of leprosy-related disabilities. This combination of knowledge and experiences strongly informed the project design related to leprosy.

The project design planned to replicate a combined approach model that Lepra had piloted in India. This model tackles leprosy and LF at the same time, as the diseases share many similarities and are often co-endemic. Government and NGO actors in Bangladesh approach LF by focusing on its prevention through Mass Drug Administration. At the time of project design, the Japan International Cooperation Agency (JICA) was responsible for management of morbidity due to LF.

Gofiran, a beneficiary with LF

There was no data available on prevalence or endemicity of LF, and the project team could therefore, not get an accurate baseline for indicator targets, particularly on estimated beneficiary numbers. Only through the actual case-finding activities, would the project be able to get a sense of the scale of the LF problem in Bangladesh.

Within this context, the project team designed a participative approach that worked with Community Champions, government, and non-government health providers, to diagnose those affected with leprosy or LF early, and to offer them quality services to manage their disease.

Community Champion checks a man for suspected leprosy

Discoveries that challenged original assumptions

The lessons learnt during the first year of implementation related to the project's approach to LF and Monitoring and Evaluation (M&E). The context of LF management in Bangladesh challenged the original assumptions in the project design. Most government health providers believed that the Mass Drug Administration programme had been successful in eradicating LF, and that consequently no further services were needed. In the meantime, JICA withdrew from Bangladesh, meaning that its LF programme providing morbidity services, completely collapsed.

The first year also demonstrated that morbidity management was of even greater importance for affected people than originally thought. Contrary to leprosy, there is no cure for LF, and project staff found it difficult to disappoint people with LF by explaining that there was no cure for them. Staff and Community Champions lacked experience working with LF and had difficulty answering technical questions from people affected or health providers. The combination of these discoveries meant that offering quality services for morbidity management gained importance in the project.

M&E was another area in which the project team made many discoveries during the first year. The remote system M&E framework was introduced late in the design process and the introduction of the framework initially required extra effort from field staff and Community Champions, who had to become familiar with many new data collection tools.

Although the system itself was piloted by Lepra previously, many of the specific tools were first trialled in this project.

The new remote system used, allowed for continuous monitoring, rather than quarterly or annually, and this introduced senior project staff to a new work flow.

The first year was a question of trial and error as to the best way to share the information collected by this system. Not only did the team need capacity-building on data collection, but they also experimented with the best ways to analyse the data so that it could easily feed back into the project cycle.

Another issue with evaluating progress in the project related to the way beneficiary indicators were defined and understood. The logframe distinguished 'screened', 'examined' and 'suspected' beneficiaries. The definition of each category was understood differently by DFID and Lepra UK compared to how it was actually used by the Ministry of Health in Bangladesh and, consequently, by project staff there. Some changes to the M&E framework were therefore necessary.

Addressing the challenges

To improve the capacity of the project team, extra training for field staff was introduced. Staff were trained on appropriate self-care techniques for LF so that they could teach people affected correctly. Senior staff members also visited a project in India, the original model for the Reaching the Unreached project, to exchange knowledge with experts there.

2 M&E trainings were introduced also:

- An introduction to the new tools
- A refresher session, once it became clear that extra support was needed

Finally, the project team decided to increase the development of information, education, and communication materials on LF. With more materials available, field staff and Community Champions were better equipped to teach others about LF.

Beneficiary Sajeran with ulcer-free feet

All these changes ensured field staff had the necessary skills required, and could then train Community Champions to help in project implementation.

The project team decided to increase the focus on morbidity management services for people affected by LF in the 2nd and 3rd project year after learning from Year 1.

Some people have complicated lymphoedema's that need repeated, long term care. Regular advocacy sessions with government health officials and providers were started to highlight the importance of morbidity management as part of the national programme on LF.

The team also decided to put additional focus on service provision in Year 2, especially follow-up visits for support. It takes a while before self-care starts showing any results, and many beneficiaries expect an immediate response. This additional service provision should prevent beneficiary disengagement with the project because of a lack of perceived change.

Finally, some important changes were made to the targeted beneficiary numbers. The original distinction between 'screened', 'examined' and 'suspected' beneficiaries are not applied in reality and are not relevant to measuring impact.

The logframe was thus adapted to refer to 'suspects referred' as the only relevant indicator. In addition, the actual numbers of leprosy and LF affected beneficiaries were significantly reduced. This reduction reflects the new definition of the indicator, as well as the trends in prevalence that were discovered in Year 1.

The activity plan was adapted to target orientation sessions to the actor groups that proved most effective in finding and supporting new cases in Year 1. The Community Champions proved even more effective than foreseen, for example.

These changes to the logframe and activity plan should ensure that milestones are achieved in Year 2 and that these milestones are a relevant representation of the project's achievements.

The results so far

Despite only recent implementation, the adaptations to the project design and logframe are already starting to show positive results.

The capacity-building in Year 1 means that field staff are now more confident and practiced in the delivery of services and activity implementation, and continuous networking and linking with government health providers is creating a positive impact on LF case management.

Following the adaptation of Year 2 and 3 milestones, the project is now on track towards achieving the Year 2 milestones, especially for beneficiary numbers. 50% of the target number for leprosy beneficiaries and 45% of the target number for LF beneficiaries were reached in the first 5 months of Year 2.

Most importantly however, people affected by leprosy and LF are enjoying a healthier life by benefitting from the project.

Like 38-year old Amina Begum, who has been suffering with LF for over 12 years. Although her leg is still hugely swollen, Amina has managed get rid of the ulcers on her thanks to self-care training from the Reaching the Unreached project. Without ulcers, she will have far fewer infections and fever attacks that come with LF.

With the adaptations in activities and outputs, the Reaching the Unreached project will be better able to achieve its ultimate objective, which hasn't changed: to reduce poverty and improve quality of life for people affected by leprosy and LF.

Monitoring progress

- The remote system M&E framework continues to be used extensively for monitoring project progress
- In addition to monitoring outputs and outcomes, Lepra has included a tool for monitoring activities on a monthly basis. This tool allows senior project staff at the local office in Dhaka and the UK office, to closely monitor activity implementation, down to a specific staff member
- Huge progress has also been made in regular analysis discussions with field staff about the ongoing progress, providing all staff with guidance if changes need to be made. The continuous analysis loop between field staff, senior project staff and the UK-based M&E specialist also enables close and effective monitoring of the project

Contact

For further information about the work of Lepra, visit their website, www.lepra.org.uk

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