

7

Lessons Learned and Future Plans



To assess the levels of awareness and motivation and the probability of sustaining the Leprosy Elimination Campaign (LEC), a feedback session for the stakeholders was organised by DANLEP MP in June 2002. However, due to inadequate stakeholder representation in this session, another session was held in early November 2002, and a questionnaire (Annex 1) was administered to obtain their views on the initiative. The feedback endeavoured to include the opinions of all categories of stakeholders. The details of the number of respondents according to their categories are given in Table 7.

The feedback questionnaire was divided into two parts. The first part sought information on the role played by the respondents during the Special Initiative fortnight, the time, effort and resources volunteered/donated and the gains and losses incurred, if any, during the process. The second part dealt with information on the evaluation/assessment of the Special Initiative campaign and the roles of the respondents as perceived by them in leprosy elimination. Analyses of the results are presented in Table 6 and are discussed in this chapter.

7.1 Stakeholder perceptions

It was an important motivation for the various stakeholders in the campaign to participate in something meaningful and socially productive. Many had an opportunity for the first time to make a difference to the society they lived in.

This indicates a latent resource for social work when the right platform is established. Given the right motivation and organisational set-up it



A camp organised by the Burhanpur Medical Store-Owners' Association.

is possible to mobilise people's participation for a multitude of activities.

It was also clear that leprosy still has a powerful stigma attached to it. This is both an asset and a liability for people's participation in leprosy elimination activities. While the strong negativity associated with the disease makes it a worthy cause and gives the participants a heightened sense of fulfilment, the disadvantage is that tremendous efforts are needed to change attitudes and build a supportive environment.

7.2 Campaign assessment by stakeholders

The feedback session involved an assessment of the campaign by various participants. The campaign was assessed on the following aspects.

1. An analysis of IEC activities;
2. An analysis of the organisation and management of the campaign;
3. Impact on awareness-generation regarding leprosy.

An analysis of the IEC

The stakeholders were divided into two groups with regard to the effectiveness of the IEC activities. Regarding the quantity some found the IEC activities adequate but others found it to be rather inadequate. They claimed that the IEC activities targeting the economically marginalised groups of people were not adequately focused. The choice

Table 7: Representation and contribution (by stakeholder category)

Stakeholder category	Nos.	Contribution	Participation level	Stated role	Documenter's remarks
NLEP, GHS, DANLEP	6	Developed the strategy, organised the core team and provided technical and managerial support	High	Helped bring together people to initiate community action for leprosy elimination	They were very active and pivotal to the initiative
Service groups	4	Support in cash and volunteers	Medium	Support in cash and volunteers	—
Trade and professional associations	3	Cash, coordination and leadership	MSOs - high NIMA - low	Cash, coordination and leadership	The Medical shop-owners were very active partners, who associated themselves from the planning stage and were also carrying on activities after the project
Political bodies	1	Support and manpower	Low	—	They were not very active and did not come for the feedback session too
Individuals	3	Credibility (in case of one prominent citizen), skilled support (planning, budgeting and logistics)	Medium	Credibility, support in planning, budgeting and logistics	Even without organisational backing they made significant contributions

Table 7 (continued)

Stakeholder category	Nos.	Contribution	Participation level	Stated role	Documenter's remarks
Religious groups	6	Supported with cash and volunteers	Medium	Supported with cash and volunteers	The religious groups that participated were those whose followers were involved
Former leprosy patients	2	None (were not involved)	—	Felt that they could have made a difference	Were called in only during feedback session

of IEC materials was another issue. The participants felt that IEC activities could have been more coordinated and focused. On the whole it was felt that while the IEC campaign did make a good impact, better planning would have resulted in more productive IEC outputs.

An analysis of the organisation and management of the campaign

DANLEP was identified as having the most pivotal role in the campaign. The whole campaign, in fact, was considered to be a DANLEP-initiated one, in which others' support had been solicited. Most of the organisers felt that the local NLEP office was facilitating this initiative. While the partners were enthusiastic and, to a large extent, the support pledged was spontaneous, the proactive role played by DANLEP indicates the current need for a dedicated and resourceful outside agency, which may not be sustainable in the long term.

People have been taking up a number of activities even after the end of this special drive. POD and Skin Diagnosis camps have been organised by some of the groups. However, without the proactive role of DANLEP it remains to be seen whether the initiative would be sustained for the period required to achieve leprosy elimination.



Feedback session with stakeholders after the intervention.

Another learning experience from the Burhanpur initiative concerned the need to actively balance the role of each stakeholder to avoid time constraints and other factors which leave a few stakeholders in control, while others may be alienated. In the case of the present project, one very active partner took over the planning, coordination and implementation of a large number of activities. While he was very effective and also perhaps the only person volunteering to put in time and the material resources needed, it sidelined some other stakeholders, whose participation then became lukewarm.

One stakeholder whose participation was crucial but insufficient was the Health Department. Most of the stakeholders felt that the Health Department needed to play a more active and prominent role, as that is what they would be required to do in the post-integration period.

The stakeholders also suggested to strengthen the inclusion of the less privileged people and LAPs in project planning and implementation before replication, particularly involving more women and, in a case like Burhanpur, the Muslim majority population.

While the Burhanpur initiative included a large number of activities, the involvement of the Muslim community in these activities was not entirely satisfactory. This resulted in fewer of them turning up at camps, rallies and planning and coordination workshops.

The Muslims in Burhanpur have distinct localities and distinct occupations and professions. More concentrated efforts with the Muslim community could have resulted in greater participation from the community, and the project's dependence on personal contacts of initial key actors could have been decreased. This is an important lesson learned for replication of the initiative in other similar urban locations.

Impact on awareness generation regarding leprosy

A unanimous opinion of all stakeholders who responded to the questionnaire was that the special initiative had raised the awareness level of the local population with regard to leprosy diagnosis and treatment.

In addition, organisations that worked on welfare issues had also become more knowledgeable about leprosy. This, in turn, created a resource base that may be useful to carry forward leprosy elimination work in the future.

7.3 Stakeholders' role

From the feedback it can be gauged that there is a lack of clarity about the role of stakeholders. While they expressed their willingness to support such initiatives in the future, most were reluctant to take on the full responsibility of organising such initiatives and felt daunted by the proposition.

Stakeholders could be seen as falling in different groups according to their perceived roles. Though the service groups such as Rotary and Lions appreciated the various aspects of the campaign and thought themselves capable of initiating and carrying out such a campaign, their ability to devote sufficient time was questionable. Trade groups such as the Burhanpur Medical Store-Owners' Association expressed their willingness to take up clearly-identifiable physical activities and outputs. They were keen to conduct activities such as POD and diagnostic camps. Health professionals and their associations were better able to appreciate the activities related to treatment and pledged their support to identifying cases and referring suspected cases to the Government Hospital in Burhanpur.

The NLEP felt that the main support needed was in patient identification and follow-up in organising POD camps. The NLEP functionaries also felt that voluntary organisations could particularly take up awareness-generation activities for leprosy elimination, as, according to them, these agencies were capable of effectively communicating with the population.

All the stakeholders felt that such initiatives needed to be sustained in order to achieve the desired elimination target for leprosy.

Annex**Questionnaire for Feedback
from Stakeholders****LEPROSY-FREE BURHANPUR CAMPAIGN**

Name : _____ Designation : _____

Institution : _____

Describe in brief your participation / contribution in the 'Leprosy-Free Burhanpur Campaign' held from 30 January to 13 February 2002

How much time did you spend in this campaign?

As a consequence of the above, how much loss (either financial or in terms of time) did you have to undergo?

How much money did you spend in this campaign (in terms of both direct cash, materials or any other indirect aid)?

What in your opinion were the achievements of this campaign?

- For yourself personally :
- For Burhanpur town :
- For the society in general:

What according to your opinion were the gaps in this campaign?

Which part of the population remained unreached in this campaign?

Who should undertake responsibility to sustain the impact of this campaign?

What are the other efforts required to render Burhanpur free of leprosy in your opinion and what will be your stated role in the endeavour?

Signature

Date : _____

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