Nepal network of leprosy NGOs

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Introduction

In Nepal several different Non Governmental Organizations (NGOs) were already assisting the government to implement the National Leprosy Elimination Programme (NLEP), but working independently in different geographical areas with very little interactions. This article describes how they developed a forum for discussion and mutual support, which led to more effective cooperation with the government authorities.

At the time of the first Donors Meeting in March 1993 held by His Majesty’s Government (HMG) at the instigation of World Health Organization, the project leaders of the leprosy NGOs were brought together and received a formal request from the HMG side for assistance in areas such as Health Worker training, public education and skin smear services. Attempts were made to assess the true situation of leprosy in all parts of the country, and this revealed a need to improve the recording and reporting system at a national level. As they began to compare progress, assist each other and seek for guidelines, the project leaders realized the long-term need for a forum where technical and administrative matters of mutual interest could be discussed. When they met for the 2nd Donors Meeting (February 1995), they established the ‘Nepal Network of Leprosy NGOs’ ('The Network’), which has endured and served for 7 years.

The basis of membership is that organizations belong to the Network and each can send two senior staff members to every meeting; larger and smaller organizations have equal representation. Honorary officers (a Chairman and a Secretary) are elected from amongst the representatives and serve 2-year terms. The original five founding member organizations received requests from other NGOs to join, and within 5 years the membership was 15. To protect the independence of individual organizations, the Network was maintained at an informal level, with no funds of its own and not seeking registration as an official ‘society’. There is no obligation on any member organization to implement recommendations of the Network, they are required only to seriously consider such recommendations in the context of their own aims and resources and Agreements with the government.
Business

Business Meetings are held at approximately 4-month intervals and last 1–2 days. They are hosted by different members on rotation and minuted by the Honorary Secretary.

For specialized matters, working groups are convened which meet separately and as often as necessary. Any member organization can nominate suitably qualified or experienced staff to attend a working group.

Matters which have been taken up and effectively dealt with by the Network have included the following medical issues: criteria for diagnosing significant reduction in a view, implication of implementing 12-month standard MDT, safe use of ‘ROM’ therapy for single lesions PB cases, efficacy of BCG as an anti leprosy vaccine. Administrative issues tackled included: differing rates of travelling allowance/daily paid by member organization for government health workers attending their leprosy training courses, revision of leprosy recording and reporting forms for use in the general health services, import and use of thalidomide, and sharing information on sources of supplies.

Special endeavours of the Network

One major undertaking successfully carried out by the Network, which would not have been possible for an individual organization, was to run a 3-day National Conference for Health Workers in 1997. Over 100 people attended; half were from Government side and half NGO staff. They presented 20 free papers, participated in workshops and seminars, and heard topical lectures by invited speakers. The Network also initiated a national ‘workshop for people affected by leprosy’, from which arose the Association for Integration, Dignity and Economic Advancement (affiliated to IDEA International) which, as a registered society itself, later joined the Network as a full member. In 2000, a training course on pre-testing of Health Educational materials was organized by the Network as a joint venture.

Relationship with government authorities

In Nepal the vertical Leprosy Control Project established in 1966 was integrated in its Basic Health Services in 1987. Since then there were very few specialized leprosy staff working in government service. Hence, the Leprosy Control Division (LCD) relied heavily on leprosy expertise available amongst NGO staff. Naturally, there was a desire to have the plan of action of NLEP carried out uniformly in all regions of the country. However, this was difficult, in view of the disparity between the leprosy NGOs implementing the programme. Each of the five original member leprosy NGOs had a different, separate, agreement with HMG and was free to work according to the policy of its parent organization within the terms of that agreement. As their styles of working and range of commitments differed, they did not wish to have any one of them as ILEP coordinator for Nepal, although all were ILEP members. When it was first formed, the Network had no intention of being a ‘voice’ for its members in response to questions from HMG. In fact, relationships between a member organization and HMG were the only topics not permitted on the agenda of business meetings. Even when several member organizations had problems with visas for expatriate staff, or renewal of their agreements, these issues were not put into the business meeting, as being too sensitive.
Initially no government representative was invited to the meeting (it was felt such a presence would be inhibiting), although a report of the main conclusions of the discussions was given for information to the Director of the Leprosy Control Division. However, when it became clear by 1997 that officers of the Leprosy Control Division would welcome the opportunity to listen to the discussions, the Director was invited to attend as an observer, or to send a colleague. This has proved profitable to both sides as a frank and cordial atmosphere developed.

Possibly influenced by observing the usefulness of the Network Meetings, the Leprosy Control Division began to call its own official ‘Co-ordination Meetings’, when it could conveniently present policies, guidelines, reporting requirements or requests for assistance to the Leprosy NGOs. As the membership of the Coordination Meetings was similar to the membership of the Network, the two meetings were often deliberately scheduled to follow each other at the same venue. This facilitated holding technical discussions on how to implement the activities required by HMG.

Gradually, the Director of Leprosy Control Division and other Officers of the Ministry of Health began to invite the Chairman (or Secretary) of the Network to speak on behalf of all partner NGOs on various occasions, for example, at the Regional Directors Meeting in January 2001 when plans for the 2nd Leprosy Elimination Campaign were discussed. The Honorary office bearers of the Network are somewhat reluctant to do this for fear of apparently making commitments that others are not prepared to undertake, so they will usually give only a very general response. However, it is felt to be a valuable sign of recognition from HMG of the resources and good will represented by the Network, when space is given at a Ministry of Health Meeting for a presentation from the Network.

The government authorities have cordially accepted help from the Network’s working group. In particular the Revised Recording and Reporting forms prepared by the Network were adopted almost unchanged by the Health Management Information Section of the Ministry of Health. When the National Manual of Leprosy Control was to be republished in 1997 and 2000, Network representatives were invited to submit suggestions for revision and to join the editorial group responsible for the manual revision.

**Conclusion**

The original reason for establishing the Nepal Network for Leprosy NGOs was simply to provide a forum for interaction between diverse member organizations. In the process of doing this, the Network also came to act as a bridge between the LCD, Ministry of Health, and the member organizations. As a result of the work carried out at business meetings and working groups, a greater degree of uniformity was engendered, and it became easier both for HMG to put requests to leprosy NGOs and also for NGOs to respond appropriately to HMG requests.

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