WORKSHOP REPORT

The experiences and attitudes of people affected by leprosy who voluntarily undertake leprosy services in Nepal

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Accepted for publication 29 August 2014

Summary This paper is a record of the outcome of a focus group discussion in which 22 leprosy-affected self-help group facilitators related their experiences and attitudes associated with leprosy services which they voluntarily undertake. Enthusiasm to undertake leprosy services was general. The principal rewards for participation in such activities appear to have been social ascendance and self-esteem. Factors cited as being most likely to further motivate voluntary service reflected the perceived importance of personal reputation and the prestige of a clear association with Lalgadh Leprosy Services Centre.

Introduction

In 2011 “Guidelines for strengthening participation of persons affected by leprosy in leprosy services” was published by the WHO. The guidelines give recognition to the potential there is for significant impact on leprosy if people affected by leprosy are themselves involved in leprosy services. The guidelines proceed thereafter with a litany of primary and operational issues that need to be addressed and suggest a number of strategies that might affect desirable outcomes. It is in the executive summary however, that acknowledgement is given to the difficult nature of the approach:

“Facilitating the participation of persons affected by leprosy is not simple. It is essential to document the process and results, provide feedback on lessons learned, and disseminate the results to a wider audience to expand the process.”

This paper was written in direct response to the call to document and disseminate relevant results. It is an account of a focus group meeting held at Lalgadh Leprosy Services Centre in

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September 2013 in which 22 leprosy-affected facilitators of self-care and self-help groups gathered for a routine feedback of the RECLAIM project. A focus group discussion on the participation of persons affected by leprosy in leprosy services was added to the agenda. All the facilitators consented to participate.

**RECLAIM: AIMS AND OBJECTIVES**

The RECLAIM project methodology was similar to that of Nepal Leprosy Trust’s Stigma Elimination Programme (STEP). STEP has been presented as a model for empowerment, disability prevention and stigma reduction. It enables people affected by leprosy/disability to manage their disability, undertake micro-enterprises, improve their literacy, access resources, become more aware of their rights and to support development in their community. Evaluation findings from STEP were used to design RECLAIM but the two projects differ in that the primary aim of STEP was stigma reduction whereas the primary aims of RECLAIM are poverty reduction and social responsibility (it is understood that stigma will be impacted by default).

At the core of the RECLAIM project is the development of self-efficacy, gained through control over impairments as an effect of self-care. Self-efficacy appears to stimulate positive identities and increased aspirations for people disabled by leprosy. It was postulated that the energy generated through sustained self-care and group support is channelled to effect self-improvement, domestic enhancement, civic responsibility and the enhancement of social harmony.

Once self-care group members have confidence and are able to prevent further impairments, RECLAIM fosters a process through which people with disability become significant change agents. RECLAIM change agents bring about developments that enhance community environments and bring about awareness of social responsibility and equity in their villages. Self-care groups evolve into self-help groups, where selected group members receive skills development and training on leadership, women’s rights, disability rights and community development. Self-help groups are supported to undertake needs assessments in partnership with government officials and community leaders to produce and implement community development plans for each village. The project facilitates access to resources and offers guidance to optimise their use. As catalysts for development, the status of people disabled by leprosy rises and they become more valued, breaking down stereotypes of dependency and insignificance.

Core activities of self-help groups include literacy programmes, management of revolving loans, and the development of micro-enterprises. The ultimate aim of the project, however, is that people with disability will be enabled to address issues of awareness, access and equity in their communities. Through appropriate development of the skills of people with disability they are able to advocate for the rights of people with disability and other marginalised groups and take their rightful place within local government structure.

**Method**

The aim of the study was to record whether leprosy affected people in the RECLAIM project were participating in leprosy services and if so what motivated them to do so and what might
be done to encourage further involvement. A directed focus group discussion was convened for that purpose.

Twenty two people who are facilitators of RECLAIM styled self-help groups agreed to participate in a focus group discussion. Almost all the dialogue was conducted in Maithili language with some recourse to Nepali when it was required (for some of the participants, Maithili was not a first language). Responses were confirmed for the principal investigator through two translators who conferred and agreed on translation.

The group comprised 21 men and one woman. They were all leprosy-affected people with a range of occupations. Ten members of the group reported that they could read a newspaper; 11 reported that they could read simple instructions. They had all partaken of facilitator training at Lalgadh Leprosy Services Centre at different times. The longer standing self-help groups were established in 2011, the most recently established groups were formed at the start of 2013.

The discussion took place in a designated training hall which is located in the compound of Lalgadh Leprosy Services Centre, Dhanusha district, Nepal.

Results

LEPROSY RELATED ACTIVITIES

As an opening exercise the participants were invited to offer a list of activities that they and/or their groups undertook, which they felt had a direct impact on the burden of leprosy in their local communities. Their list follows:

1. Group Meetings (it was explained that facilitating self-care and self-help groups had given them confidence and that confidence had lead them to be bold about leprosy in the first instance).
2. Self-care (as applied by individuals and in groups).
3. Raising social awareness regarding leprosy related issues.
4. Examination of suspect leprosy cases and referral to health facilities.
5. Facilitating access to government resources.
6. Ensuring access to referral centres for the treatment of complications.
7. Conducting home visits to ascertain whether or not people are gaining access to services that are available.
8. Advocacy for the enactment of rights that are enshrined in government policies.
9. Follow-up of current cases to ensure compliance and to prevent default.
10. Assistance to secure disability cards.
11. Activities to reduce stigma.
12. Counselling.

A brief exercise was undertaken to ascertain how many of the facilitators were engaged in each activity (Table 1).

ENABLEMENT

The group was then asked to explain what factors had enabled them to offer the types of services they undertook. The factors suggested, with the elaborations given, are listed below in the order cited:
1. **Self-care**: The efficacy of the intervention was beyond dispute for them and that conviction had given them confidence to encourage others to apply themselves to it. They felt able to exhort others with leprosy related impairments to prevent further impairment themselves.

2. **Training**: All facilitators had received training in the identification and treatment of leprosy and its complications from the training centre at LLSC.

3. **Exposure visits**: Visiting other self-help groups had enabled them to share experiences, learn and encourage each other.

4. **Specific self-care training**: All facilitators had availed of a 14 day course in self-care at LLSC. This was considered to have been foundational for many.

5. **Economic support for income generation**: Finding time to devote to leprosy activities demands significant personal sacrifice, but this is alleviated by being able to avail of loans for income generation projects (the RECLAIM project supplies seed money to enable self-help groups to extend opportunities for income generation projects).

6. **Provision of bicycles**: The RECLAIM project provides each facilitator with a bicycle. This provision enables them to travel more speedily than would otherwise be possible and therefore reduces the time demand.

7. **Savings and Loan programme**: These features reduce the stress of financial constraint that would otherwise prevent altruistic activities (savings and micro-credit unions provide security against crises. Members can apply for loans from group savings to cover emergency situations).

8. **Non-formal education**: It was explained that literacy skills *per se* reduce stigma but also that non-formal adult literacy classes are conducted for mixed groups and that this too reduces stigma.

9. **Provision of labelled bags**: Each facilitator is supplied with a bag in which to carry books and documents. The bags are clearly labelled to identify the carrier as a RECLAIM group facilitator. On each bag RECALIM is briefly described as a project of Nepal Leprosy Trust. It was explained that carrying the bag gave them a sense of status.

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**Table 1. Leprosy services undertaken**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number of facilitators who are actively implementing the activity</th>
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<tbody>
<tr>
<td>1  Group Meetings</td>
<td>22</td>
</tr>
<tr>
<td>2  Self-care (as applied by individuals and in groups)</td>
<td>22</td>
</tr>
<tr>
<td>3  Raising social awareness regarding leprosy related issues</td>
<td>20</td>
</tr>
<tr>
<td>4  Examination of suspect leprosy cases and referral to health facilities</td>
<td>21</td>
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<tr>
<td>5  Facilitating access to government resources</td>
<td>17</td>
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<tr>
<td>6  Ensuring access to referral centres for the treatment of complications</td>
<td>14</td>
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<tr>
<td>7  Conducting home visits to ascertain whether or not people are gaining access to services that are available</td>
<td>13</td>
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<tr>
<td>8  Advocacy for the enactment of rights enshrined in government policies</td>
<td>14</td>
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<tr>
<td>9  Follow-up of current cases to ensure compliance</td>
<td>8</td>
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<tr>
<td>10 Assistance to secure disability cards</td>
<td>10</td>
</tr>
<tr>
<td>11 Activities to reduce stigma</td>
<td>22</td>
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<tr>
<td>12 Counselling</td>
<td>20</td>
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10. **Provision of footwear:** It was explained that the timely provision of subsidised footwear was very important. Facilitators advise people to wear footwear and direct them to sources where it is expected that good protective footwear will be available. If people travel to find that they are not able to avail of the footwear as and when required they become disillusioned.

11. **Being leprosy affected:** It was suggested that having an intimate knowledge of the effects of leprosy makes some people determined that others will not become similarly impaired or disabled. Being leprosy affected, therefore is in itself a powerful motivating factor to become engaged in leprosy reduction activities.

**COMMUNITY TRUST**

The Facilitators were then asked whether they felt they were trusted by the community or not. They unanimously and emphatically responded that they did feel trusted. That response was followed by a further question which sought to establish how they felt they had established that trust. The following responses were given:

1. **Services are free:** The facilitators do not charge fees or seek recompense in any manner whatsoever. This commitment appears to have earned them respect.
2. **Sanitation Programmes:** A number of groups had undertaken ‘village clean-up’ projects. They exhort their self-care or self-help groups to take responsibility for the collection and disposal of garbage and for creating more hygienic village environments. In some situations ‘clean-up’ campaigns have successfully attracted the attention of local government officials who have given support and assistance.
3. **Active involvement in matters of civic importance:** Local issues arise which may need specific action. Taking the initiative to resolve such issues appears to have given some groups significant kudos. An example of one situation was that a village had become infamous for ‘hooking electricity’ (a dangerous and unlawful pilfering of electricity). Through the actions of that village’s RECLAIM group the activity was curtailed.
4. **Transparency:** All matters pertaining to RECLAIM self-help groups are conducted with transparency, consequently they have become trusted institutions and are frequently extolled by local government bodies.
5. **Advocacy:** Having gained confidence and self-esteem many of the facilitators have advocated for justice and rights for others in their communities who are not leprosy affected. This too appears to have won them admiration and respect.

**CASE FINDING**

The facilitators were asked how many people had visited them to seek an opinion about skin conditions that might be leprosy. The total number seeking consultation was not recorded but the number of people referred as suspect cases and the subsequent number of positive diagnoses was recorded.

Two hundred and eight people had been referred by 17 facilitators to health institutions when they suspected leprosy. Of that number 99 (47%) had been confirmed as cases of leprosy.

When comparing case detection activity rates between the facilitators a wide difference was noticed. One explanation is that some groups had been established for longer than others
(some groups started at the beginning of 2011 whilst others started in 2013). It is also likely that some facilitators were more competent than others or that some were trusted above others. Another issue is that whilst registered cases could be verified, there is no way of ascertaining whether others who were sent to health posts did or did not have leprosy (some health posts may have lacked capacity to diagnose).

**Enhanced Motivation**

The facilitators were asked what might make them even more effective in their activities and endeavours. They volunteered the following suggestions:

**Uniform:** The facilitators derive status from being known as RECLAIM facilitators. Status is a powerful motivator for them. They suggested that uniform would make them even more recognisable.

**Group Meeting Houses:** Many groups meet in public places which are sometimes required for other purposes. It was also felt that local group meeting houses would add validity to their status as serious civic minded bodies because they could allow the houses to be used by others too.

**Mobile phones:** More efficient communication would be advantageous to everybody.

**Salary:** Some suggested that being given a salary would enable them to be more active.

**Construction of toilets:** Toilet construction in the districts where RECLAIM is active has become a major issue. The facilitators felt that if they could be involved in facilitating toilet construction it would directly benefit their communities and would raise their status.

**Discussion**

The authors accept that the outcome of a focus group discussion offers a perspective that may be limited to what the participants want others to know and that it may not necessarily reflect all that could be known. We also advise that the purpose for convening a focus group discussion and the venue at which a discussion takes place is likely to influence what is said and what is not said. These issues, furthermore, are likely to be magnified if the participants, as in the case of this study, have vested interests in impression creation. It is within those limitations that we offer the discussion that follows.

It is important to establish that the RECLAIM project was not initiated with the specific intent of engaging people in leprosy services (other than self-care group facilitation). The groups were encouraged to be involved in community activities, but the precise nature of such activities was not prescribed. It is through initiation and involvement in community activities that the groups demonstrate the balance between rights and responsibilities that appeared to win them high regard from their communities and local government institutions. The self-help groups, however, make their own decisions about how they might become engaged in civic minded initiatives. When asked why they felt trusted in their local communities the group cited acts of civic responsibility that they had undertaken as reasons. Trust and high regard in their communities appears to be a strong internal motivating factor for involvement in productive initiatives generally, including ‘leprosy services’.

When asked what might encourage them to be even more engaged in “leprosy services” they began their response by restating that their status in their communities was of primary
importance to them and that, with a general commitment to helping others with leprosy, was sufficient motivation. They then proceeded to give other suggestions, but it was interesting to note that most of the suggestions they made were actions or developments that would either raise their status further or make them more efficient.

As interest in the mobilisation of people affected by leprosy begins to gather pace so does debate on how to motivate, incentivise and reward people for the leprosy services they give. The authors cautiously suggest that recourse to psychological perspectives in understanding such issues is enlightening. In his seminal work, Maslow theorised that esteem and self-actualisation are essential if people are to live fulfilled lives, but he also suggested that those higher aspirations can only be achieved if more basic needs are secured first (i.e. physiological needs and the need for security). It is important, therefore, to ensure that people who might be mobilised for voluntary service should be free of concerns about the provision of basic needs. Where such needs are met, however, cash incentives given with the aim of stimulating motivation may be unsuccessful or even disadvantageous.

As with Maslow, Herzberg’s studies of motivation in 1959 are considered seminal. Herzberg suggested that whilst certain essential factors, including payment, are required to allay dissatisfaction (dissatisfaction results from their absence), it is an entirely different set of factors that evoke satisfaction and motivate people to higher performance. He recorded, for example, that factors that include acknowledgement of achievement, recognition and responsibility are powerful motivators, as are open channels of communication and a sense of contribution to team effort. (These features were found in diverse work environments in different countries and therefore strengthened the validity of his earlier work on motivation.)

More recently, Cho and Perry demonstrated that when workers have little interest in external rewards, their intrinsic motivation has a substantial positive effect on how they apply themselves to their work. When employees focus on external rewards, however, the effects of intrinsic motives on engagement are significantly diminished. They found that workers who are intrinsically motivated are three times more engaged in their tasks than employees who are extrinsically motivated.

The results of a study by Deci et al. showed consistent negative effects of incentives on intrinsic motivation. More specifically, their study demonstrated that for every standard deviation increase in reward, intrinsic motivation for interesting tasks decreased by about 25%. When rewards are tangible and foreseeable (i.e. if subjects know in advance how much extra money they will receive) intrinsic motivation was shown to decrease by 36%.

In summary, it appears that people are more likely to enjoy their work and therefore apply themselves to it, if they are able to focus on the work itself and that they are less likely to enjoy their work if they focus on monetary reward.

The RECLAIM self-help group facilitators are able to avail of micro-finance loans and they are given a modest stipend, but they receive no other financial incentive or material reward. Some did suggest that ‘salary’ would motivate them to greater effort, but the research cited here suggests that it would not, unless their physiological and security imperatives are significantly compromised. It is not suggested here that people should be exploited because they derive pleasure from their tasks, but that monetary reward may not be the most effective or even the most desirable recourse for stimulating greater motivation. More creative methods that further enhance self-esteem and public acclaim may perhaps be more appropriate. We caution, however, that the stimuli that motivate people might not remain the same over a long period of time. A heightened esteem might be a relatively temporary phenomenon.
Conclusion

A focus group discussion produced feedback that suggested that people affected by leprosy can be effective agents to promote and conduct leprosy services, but that the dynamism that generates and sustains such actions is primarily the esteem that they earn from demonstrating civic minded commitments. Facilitating opportunities to promote participation in the social spheres of community generally should perhaps be given priority before attempting to initiate leprosy services through the agency of people who are, or have been, stigmatised by leprosy.

References

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