CASE REPORT

Journey of empowerment: a case study of the Association of People Affected by Leprosy (APAL), India

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Accepted for publication 4 December 2018

Introduction

Strengthening the participation of persons affected by leprosy in the provision of leprosy services has been strongly supported by World Health Organization. The Bangkok Declaration and the more recent WHO Global Leprosy strategy (2016-2020) urged governments and national programmes to respond. However, this was never going to be a simple task, and there is a need to document both process and outcomes, provide feedback on the lessons learned, and disseminate the results to a wider audience, in order to expand the process.

In India, previous experience, particularly regarding HIV and AIDS, informed us that an empowerment paradigm usually shifts progressively from an initial focus on ‘securing a voice’ and ‘building the capacity of individuals and communities to promote health’, towards ‘inclusion’ and ‘representation’ at local, national and international forums, and finally ‘collective transformation and mobilization for health’. This framework of progression within an empowerment paradigm, as shown in Figure 1, has been helpful as we considered the involvement of persons affected by leprosy in the leprosy services as well as in leprosy control programme and strategies.

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This case-study of the Association of People Affected by Leprosy (APAL) in India has been developed to illustrate a current example of the empowerment process and how it could be institutionalized.

Material and Methods

From the archives of the Society for Leprosy Affected People (SLAP) and APAL’s Hyderabad office, all available internationally and nationally published and unpublished manuscripts in English describing the work of SLAP and APAL over a 13-year period starting from 2004, were collected. In total, twenty-two such manuscripts or documents were reviewed. The relevant contextual and factual details were clarified by conducting several face-to-face interviews. These twenty-two manuscripts were imported into MAXQDA (version 18·0), a software programme for qualitative data management. All the imported documents were coded after reading and re-reading, following an open-ended coding system. The theoretical framework of progression within the empowerment paradigm was applied to track the progression, transition and transformation of APAL along the journey to empowerment. Qualitative thematic analysis was undertaken with the help of the coded data to clarify aspects of genesis and SLAP’s commencement journey, its association with National Forum India (NFI) and thereafter its evolutionary transformation into APAL.

Results

To better understand the historical context, the following summary taken from the report on study of leprosy colonies in India (2005–06) provides useful insight.

**Context: leprosy colonies.** Among the States in India, in the late 1970s and early 1980s, Tamil Nadu had the largest number of persons suffering from leprosy, with about 800,000 patients. Stigma in Tamil Nadu was also very high for various reasons, including the low public awareness of the scientific facts of leprosy and the fact that there were no drugs available at that time for definite cure of the disease. As a result, there was so much fear about the disease among the general public that persons afflicted with leprosy were segregated from their families and communities. In some cases, the patients themselves left their families to save them from social ostracism. There was no law to compulsorily segregate patients from the community but they were frequently abandoned by the community due to fear of the disease. Husbands could easily abandon their leprosy affected wives; in some cases, parents...
even disowned their children; sons and daughters were unable to support their aged leprosy affected parents due to economic reasons and social stigma. At the same time, there was no Government leprosarium to admit and care permanently for patients abandoned and neglected by the community, so many were forced to beg for their living. They started to beg near tourist sites, Hindu temples, churches, mosques, bus and railway stations, on the streets, etc. In these places, they met each other and started to live as groups. They married among themselves and started to have children, forming their own families in these informal ‘leprosy colonies’. Since the community did not want them, they started to live away from the towns and cities, often nearer to the big leprosy hospitals. These places in due course became known as “leprosy colonies”. Begging and leprosy reduced their social status in the community and they were completely isolated socially.

Neither the Government nor the NGOs took any initiative to ameliorate their sufferings, and they developed an attitude against the Government. They were also sometimes forced to indulge in some anti-social activities. Public opinion about these colonies was consequently not good. In some places faith-based organizations helped them to construct houses and provided medical treatment. But by and large these leprosy colonies were highly neglected and very little attempt was made to study them or the conditions prevailing in them, until a national survey was proposed and carried out (2005–06), which documented that there were 631 leprosy colonies, out of which the majority (81%) were run and managed by residents of the colonies themselves.

I. PROGRESSION WITHIN THE EMPOWERMENT PARADIGM

A) Securing a voice: genesis of the Society for Leprosy Affected People (SLAP)

Of the 631 leprosy colonies nationwide, there are currently 98 leprosy colonies in Andhra Pradesh and Telangana State, with a total population of approximately 20,000 leprosy affected persons living in them. Starting from 2004, one of the authors (VN) organized a number of rallies to create awareness, so that leprosy affected persons could receive benefits from the government. He started his first groups in a few sub-districts of Hyderabad, where he was then living. One of his early actions was to organize a rally in February 2004 seeking an increase in the disability pension which the State government paid to persons affected with leprosy. This was duly achieved when the amount was raised from 200 to 500 rupees.

In 2006, a community based organization named SLAP (Society for Leprosy Affected People) was set up to promote a better quality of life for the persons affected with leprosy, in the Indian state of Andhra Pradesh. It was the first organization of its kind in India, in which all members were affected by the disease.

In 2007, SLAP managed to get 5000 leprosy-affected people to a rally in central Hyderabad. SLAP campaigned successfully to get all leprosy-affected people a free bus pass. “It may sound like a small thing, but when you have to walk three hours to get to the nearest town, something as simple as a free bus pass can revolutionize your life”. SLAP also got the government to agree to offer 5000 leprosy-affected people in its area of operation a disability pension. This was the equivalent of raising £50,000 every month and putting it straight into the pockets of those who need it most. It meant thousands of elderly and disabled people affected by the disease no longer needed to beg for a living.

In September 2011, the SLAP team met Human Rights Commissioner Shri. K. P. P. Reddy regarding the violation of human rights of leprosy affected persons. SLAP was then
supported by LEPRA India Health in Action and the Sasakawa Memorial Health foundation (SMHF). With the help of these organizations, training programmes, livelihood and self-employment workshops, and awareness programmes were organized.

B) National Forum India

SLAP became a board member the National Forum India office in Delhi, which was the nationwide informal networking organization of persons affected by leprosy. National Forum of India, although informal, was then regarded as the third well-established forum for leprosy affected persons, the first two being in Japan and Brazil. In 2012, the office of National Forum India moved to Hyderabad where it was registered as the “Association of People Affected by Leprosy” (APAL).

C) Capacity building of APAL

APAL proved to be a supportive fraternity for both Government and Non-Governmental organizations and communities through its effective coordination and sustained advocacy efforts. A major challenge was to make the representative leadership continuously accountable to individuals, families and communities, and yet at the same time promote a cohesive participatory forum for genuine representation and advocacy. In view of these issues, the leadership at APAL focused on matching community needs with available public domain services. The APAL leadership further worked on a systematic regionalization-institutionalization approach for services utilization.

A major turning point was ‘multi-purpose integration’ which included integration of existing resources and collective leadership-based advocacy among concerned departments, welfare offices and local community leadership, which helped to promote mutual accountability, especially in terms of extension and provision of services to leprosy affected people.

Following this approach, APAL now is working with the Central and State Governments for the empowerment of people affected by leprosy. APAL is present in 23 States of India and works with Sasakawa India Leprosy Foundation (SILF) towards the economic rehabilitation of people affected by leprosy who live in leprosy colonies, and in the implementation of His Holiness the Dalai Lama and Sasakawa Scholarship program for the benefit of children who live in the leprosy colonies in India. APAL is supported by The Nippon Foundation, Japan for its various programs.

In October 2014, a Human Rights Training Programme was organized by APAL for workers and NGOs working for leprosy affected persons. In October 2015, a sit-in protest was organized in Bhopal Madhya Pradesh for pension enhancement of persons affected by leprosy.

II. TRANSITION AND TRANSFORMATION WITHIN THE EMPOWERMENT PARADIGM

A) Representation of APAL at National and International levels

Today, APAL is not only a source of immense support for persons affected by leprosy, its presence is increasingly being felt in policy circles within the country and beyond. Laws exist in many countries under the World Health Organization’s (WHO) South-East Asia Region that discriminate against leprosy-affected people and their families. These laws impact
chances of employment, marriage and other areas. In this regard, APAL presented their case before the Law Commission of India headed by Justice Ajit Prakash Shah in 2014–15, leading to the report no. 256 titled, “Leprosy Affected Persons and the Laws applicable to them” being submitted by Justice Shah to the Central Government of India, on 7th April 2015, with a clear recommendation to act urgently to enact a comprehensive law eliminating discrimination against persons affected by leprosy.

**B) Collective transformation and mobilization of health and other social resources through advocacy efforts**

The review of day-to-day activity diaries, proceedings, and annual and quarterly progress reports of APAL detailing various activities maintained over the period of more than a decade, revealed SLAP and APAL’s team work and contributions, which enabled a wide spectrum of services for persons affected with leprosy, ranging from advocacy on various platforms up to consistent work on the ground. APAL facilitated issuance of Antyodaya cards, helped in ensuring rehabilitation and accommodation, disability certificates, reservation in employment, caste-certificates and free electricity. APAL facilitated pensions and got loan-waivers and rights for persons affected with leprosy as disabled persons. Getting sanction for bus stops, to having bus shelters, getting approval for water lines and graveyards, to getting bandages and medicines, APAL also facilitated blankets and clothes as in-kind donations to the colony residents.

**C) Collective transformation and mobilization of health and other social resources through actions at the grassroots level**

On the ground, APAL kept on approaching new cases of leprosy and facilitated early treatment, support and care. APAL made tremendous efforts to facilitate livelihood opportunities for leprosy affected persons by planning and facilitating income-generation trainings to persons affected with leprosy at colonies. APAL strongly advocated for rights of persons affected with leprosy at colonies for earning livelihood, medical-aid and education for their children.

**Journey towards Empowerment: Vision of future work and priorities:** A top priority is that all those developing leprosy should be diagnosed and treated as early as possible, so that they would not suffer from any disability. They should be fully integrated into society, as they are no longer a threat to society. They are just as any normal human being.

Progression towards empowerment was assessed with the help of six outcomes regarded as initial, intermediate and final. Figures 2, 3 and 4 helped us to understand through illustrative examples, the progression of persons affected with leprosy within the empowerment paradigm. It clearly showed across all the six outcomes there is a definite progression towards empowerment. There is welcome institutionalization of this empowerment with increased coverage, reach and presence of APAL in India.

**Discussion**

This case study served two purposes: firstly it helped us in documenting the contributions of SLAP and APAL in the field of leprosy in India and secondly it helped us to understand the journey of progression of persons affected by leprosy within the empowerment paradigm.
APAL is advocating for people’s rights not only at local or State levels but at National and International levels. This case-study captures the impetus and the aim for the initiation of SLAP which was to provide and promote a better quality of life for leprosy affected people and to strive towards restoring hope and dignity for them and their dependent families. In a socially stigmatizing society the endeavor was to retrieve basic health rights and avail social welfare measures to improve their life. APAL now has newer mandate of ensuring a happy and stigma-free life for all people affected by leprosy. This case-study also provided us a classic example of the innovative approach of advocacy with strong grassroots connections,

**Figure 2.** Empowerment journey of APAL vis-à-vis to outcomes on the trajectory of progression, transition and transformation.

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**Figure 3.** Empowerment paradigm elaborating on Securing voice as initial outcome and Representation and Collective Transformation and Mobilization of Health and Other Social Resources as intermediate outcomes.
which led up from the street to the highest law-court in the land. It also made us realize how adaptive, flexible and in a good sense ‘opportunistic’ any worker, leader or institution in the field of leprosy should become, in order to safeguard the interests of those affected.

While better funding has been assured more recently, APAL had very little economic viability at the start, hence from the day one, the focus was on integrated planning and the re-integration of socially isolated individuals into their own communities and the re-integration of dependent families into the mainstream of society. APAL now focused on unmet community needs, available public domain services and coordination management. APAL further worked on developing regional networks and nurturing these through institutionalization, leading to sustained utilization of services. APAL envisioned multipurpose integration as paving the way to convergence and integration of existing resources, leadership-based advocacy and activism among departments, welfare offices and local community leadership, which helped to promote mutual accountability in the provision of services.

This case study also enabled us to apply a framework of progression of affected persons within the empowerment paradigm. Further progression and sustainability of empowerment needs to be continued and in that regard, there is an increased role and responsibility of National and State Governments as well as International policy-making and policy-influencing agencies and institutions.

**Conclusions**

This case-study is one of the many ongoing initiatives to document the work undertaken by APAL in India. It shows that APAL is not only a source of immense support for persons affected by leprosy, its presence is increasingly being felt in policy circles within the country and abroad. However, there is a further need to replicate such case-studies in different regions of India to best capture the progression of movements of persons affected by leprosy in India within the empowerment paradigm.
Acknowledgements

We gratefully acknowledge members of ILEP Temporary Expert Group on strengthening participation of persons affected by Leprosy, the work of developing this manuscript would not have been possible without the wholesome support and valuable comments of these expert group members. We the authors of this manuscript herewith express our gratitude towards Ms. Hiroe Soyagimi, Ms. Kerstin Beise, Dr. Hugh Cross, Dr. Michael Chang and Dr. VR Pemmaraju.

References

1 World Health Organization Regional Office for the South-East Asia. Guidelines for strengthening participation of persons affected by leprosy in leprosy services. 2013 [cited 2017 Jun 6]; Available from: http://apps.who.int/iris/bitstream/10665/205169/1/B4726.pdf?ua=1he
6 Parker RG. Empowerment, community mobilization and social change in the face of HIV/AIDS. Aids. 1996 Dec.