



Fighting disability and stigma from leprosy in India

Lessons learned

The project demonstrated that leprosy had to be regarded not primarily as a medical problem but a social problem. This meant that raising awareness about the curability of the dreaded disease, fighting stigma and discrimination, dispelling fears and demonstrating that it was possible to live a normal life during and after treatment for leprosy had to come high on the agenda of the project.

The project showed that innovative approaches such as street performances, home visits, folk music, enrolling cured patients in the project activities, “trialogs” among patients, health staff and villagers, gender specific problem solving, and leprosy camps that demonstrated that patients could safely be integrated in daily life, created an environment that allowed the project to reduce leprosy prevalence from more than 50 cases to around 1 case per 10.000 people.

Background

Through the ages, leprosy was one of the most feared diseases because of the deformation and disability it caused. Leprosy was primarily a disease of the poor, and this contributed to the stigma that patients suffered. The early 1980s saw the advent of the WHO-endorsed multidrug treatment schedule that proved highly effective. This revolutionized the treatment, but success was not automatically guaranteed, mainly because of the huge difficulties in changing people’s perception of the disease.

From the start, Danida’s support to the fight against the disease was designed as a support to India’s own National Leprosy Eradication Programme (NLEP). It stretched over 18 years from 1986 till 2003.

Location:

India

Title:

Danish Assistance to the National Leprosy Eradication Programme (DANLEP)

Year of implementation:

1986-2003

Funding:

DKK 76 mill (USD 12 mill)



Photo: DANLEP

A cured person speaking about her treatment for leprosy.

Objectives of the project

- To support NLEP in its general aim to reduce prevalence of leprosy by interrupting the chain of transmission of *M. leprae* to the extent that it will not be a major public health problem by the end of the century and to maintain that situation thereafter
- To provide pragmatic assistance to NLEP with respect to leprosy elimination and the development of strategies for prevention of a possible consequent resurgence
- To develop in the states of Orissa, Madhya Pradesh and Tamil Nadu appropriate modalities for integration in collaboration with the parties concerned

Main activities include

Infrastructure

- Ensure uninterrupted supply of Blister Packs for multidrug therapy (the blister packs were a Danida-initiated, major innovation of the treatment protocol world-wide).

Human Resource Development

- Facilitation of regular zonal, inter-zonal and local meetings to promote needs assessment studies on training needs, training, and development of training modules.

Supplies

- Funding of supportive drugs, footwear, dressing care, and corrective surgery.



IEC

- Production of Information, Education and Communication materials for use at the innovative IEC activities.
- Enlisting the services of local agencies with a proven track record in social marketing to develop a campaign using strategies that are expected to emerge as a result of the proposed workshop on urban leprosy control.
- Development of an IEC kit for the national programme on early case detection and counselling skills which will be implemented by general and primary health care staff.
- Involvement of community by IEC through training, media, workshops and consultancies.

Monitoring and Evaluation

- Assist in the development of a substantially simplified reporting system for leprosy, which can reflect due attention to issues of gender equity, to be used by the general health services.
- Assist in development and design of an epidemiological model for assisting NLEP in designing adapted control strategies after achieving elimination target.
- Facilitate the development of a national network of sentinel units.

Health Systems Research

- Development of appropriate protocols for applicability of models for integration, issues of gender equity and programme sensitivity to vulnerable groups, and cost-efficiency of the project interventions.

Integration

- Preparation of integration of project activities into general health system.
- Phasing out.

Other Lessons Learned

- The constant combination of information, education and treatment used in the leprosy camps proved very effective in reducing stigma. The leprosy camps were camps where the participants lived for a while, and where the community could experience patients, treatment providers and community members live and eat together. In the camps it was possible to actively participate in cleaning and treating patients' wounds and massage their disabled hands and feet – physical contact became non-threatening. The reduction of stigma meant that many patients were reintegrated in their families and that more patients came forward for treatment.
- The project showed that a donor-funded project can be very useful in trying innovative methods which, when they have proven their efficacy, can be integrated into the government's disease control activities.
- The lessons learned in DANLEP of making the services patient friendly through IEC, community mobilisation, gender aspects and development of trust between patients and providers, use of blister packs, coloured patient cards, patient medicine boxes containing the entire treatment drug quantity, and ultimately mainstreaming of project activities into the general health care system, were later used in the Revised National Tuberculosis Control Programme in India.

Further Reading:

[Sundaram C, Narayan G. The DANLEP experience 1986-2003. DANLEP New Delhi 2003](http://www.danlep.org/publicctn/expernce/summary.pdf)
<http://www.danlep.org/publicctn/expernce/summary.pdf>
[Project Completion Report \(Draft\) 5.5.2004](#)

The National Leprosy Eradication Programme
www.danlep.org

Danish Embassy, New Delhi:
www.ambnewdelhi.um.dk

Danida File No.:
Ind.104.121