### Leprosy in Bangladesh 2014: a situation analysis

#### Background

Last year, 3,140 new cases of leprosy were detected in Bangladesh, of whom 166 (5%) were children and 340 (11%) were registered with grade 2 disabilities. The level of grade 2 disability has remained higher than 10% since 2007.

Because of the declaration of “elimination” (fewer than 10 cases per 100,000 population) in 2000, there has been a decrease in allocation of funds for the national programme and leprosy has lost its place as an important infectious disease.

#### The survey

The analysis was conducted from January to June 2014 by Lepra and other partners in collaboration with iccdr,b a long established research organisation in Bangladesh. Ten districts were selected randomly in proportion to population size from high, medium and low endemic areas of the country. Bogra and Moulvibazar were pre-selected because a pilot leprosy integration project will be implemented in these two districts.

There were many aspects to the analysis. Here we have highlighted the “people’s perspective” (1146 people interviewed) and the “patients’ perspectives” (30 exit interviews).

#### The findings

The most common source of information about leprosy was from neighbours and relatives. There was a very low level of knowledge about the key signs and symptoms of leprosy. Only half of the survey participants thought that people affected by leprosy could live a normal life.

For people affected by leprosy, the disease is still a barrier to continuation of education, employment and participation in social events.

#### Disease

Many cases are missed because of the passive method of detection. Recording and reporting systems were the major weakness at all types of healthcare centres and there is a lack of uniformity.

Delays in diagnosis are caused by the lack of both skilled government health staff and outreach activities. The skills of leprosy programme-specific staff were found to be good. Appliances for sensitivity testing were not always available.

There is a delay in seeking initial care because of a lack of information and awareness about what is available and a lack of understanding about the urgency. At the initial stage of the disease, most people are not concerned about it because it does not hamper their day-to-day life. Some seek help from homoeopathy practitioners or non-specialist clinics and are wrongly diagnosed.
Knowledge about types of leprosy, key signs and treatment was inadequate amongst healthcare staff, other than Leprosy Control Assistants. Clinicians do not encounter leprosy in their day-to-day practice and often cannot differentiate between leprosy and other skin conditions. There is a lack of skilled staff capable of making a quick diagnosis and the referral chain is not working well.

Facilities for management of disabilities and complications such as ulcers were not available in most of the healthcare centres and hospitals visited.

Nearly 80% of the cases are diagnosed and treated by the non-governmental partners despite the integration of leprosy into the government health system.

**Poverty**

Leprosy is endemic in the poorest districts of Bangladesh.

Socially marginalised groups such as women and the urban poor are less likely to attend for care.

Most of the people interviewed were poor, had little or no education and engaged in manual labour. People with lower nutritional status are particularly susceptible to leprosy.

Leprosy continues to act as a barrier to education and employment. Eleven per cent of the people affected by leprosy had discontinued their education; the main reason for this was disability, closely followed by family disapproval. Twenty-nine per cent were not able to work due to disability, inaccessible infrastructure, negative attitude or family problems. Poverty is both a cause and consequence of leprosy and families are driven deeper into it by the lack of education and income.

**Prejudice and self-esteem**

The survey sought the views of patients through interviews as well as through in-depth case studies. A high level of stigma prevails in communities, which creates barriers to participating fully.

Only 57% of the people interviewed agreed that a person affected by leprosy should be respected like other people, including 11% who would refuse to maintain contact and 29% who would refuse to buy from the person. Thirty-two per cent would refuse to travel in their company and 10% would exclude the person from a community event.

**The needs**

Early detection of symptoms, early diagnosis and treatment are the keys to prevention. A programme of active case detection is urgently needed. It is very important to maintain the programme efficiency and the capacity to detect and treat all new cases in all existing facilities.

Prevention of secondary disability for those who already have primary disability after multi-drug therapy is important, including management of ulcers. Specialist services and even basic services like ulcer care need to be integrated into the general healthcare system.

The outreach programmes need to be strengthened to provide information and dispel myths and misperceptions. A media campaign is crucial to raise public awareness and a school-based curriculum needs to be introduced.

It is a major challenge to sustain the knowledge, skills and experience in leprosy management, particularly in prevention and management of disability.

Community rehabilitation, including skills training for income generation, is a priority for people living in poverty, exacerbated by the effects of leprosy.

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Our impact

We are integrating our activities and those of our partners into the government programme to ensure long term sustainability. Dr Mong, the country director of Lepra Bangladesh chairs the Leprosy and TB Country Co-ordination group (of the National Leprosy Elimination Programme) and is a member of its Technical Interest Group.

In 2013-14 we worked with 155 self-help groups for people affected by leprosy. These groups, with 1,609 members, have led to remarkable improvements in standards of living and quality of life through community empowerment and poverty reduction activities. Over the last three years, our approach in Bogra district has, on average, increased beneficiary income by one third.

Our community education and awareness activities, including school events, encourage people who are worried about symptoms to come forward for diagnosis. We also train healthcare staff and community workers, contributing to reduced discrimination.

We work with networks of people living with the effects of leprosy to enable advocacy meetings with authorities and policy makers. This gives network members the opportunity to speak out with a stronger collective voice to demand their rights.

Explanation of terms

Leprosy

Leprosy is a chronic disease caused by a slow multiplying bacillus, Mycobacterium leprae. The incubation period can be up to 20 years.

The disease mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract and also the eyes.

Leprosy is completely curable through multi-drug therapy which has been available in Bangladesh since 1985.

Grade 1 disability

Anaesthesia (numbness) but no visible deformity or damage.

Grade 2 disability

Visible deformity or damage present

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