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Interviews with two key leaders in leprosy: Professor PL Joshi and Professor Maria Leide

The International Leprosy Congress (ILC) in Hyderabad (30th January to 4th February 2008) was an opportunity for the leprosy community to come together and share experiences, ideas and examples of best practice. The congress also provided an environment in which politicians, policy makers, field workers, researchers and leprosy affected individuals could interact directly with one another.

The Leprosy Review Editorial Board agreed at its meeting prior to the congress that the ILC was an excellent opportunity to obtain the current views of the National Programme Managers of India and Brazil, the two countries which contributed 71% of the new cases reported in 2006. The ILC was not just a convenient location, more importantly it was taking place during a time of significant change: given the process of implementing the recently adopted Global Strategy for 2006–2010, India having achieved the World Health Organization (WHO) defined elimination target and continuing concerns in the leprosy community about integration.

Dr. P. L. Joshi and Dr. Maria Leide W. de Oliveira were contacted prior to the congress and both kindly agreed to discuss issues concerning the leprosy programmes in their countries. They were each interviewed using a set of questions compiled by members of the Editorial Board.

Dr. Joshi was Professor of Community Medicine in Allahabad for 12 years. More recently he has been Technical Director of the Indian National AIDS Control Organisation and also for vector borne diseases. He had been National Leprosy Programme Manager at the Indian Ministry of Health for six months prior to the congress.

Dr. Joshi highlighted the major challenges facing the Indian National Programme as the full integration into mainstream society of leprosy-affected individuals, keeping leprosy issues high on the health agenda with continued commitment from political leaders and the full integration of leprosy care into general health services. The point when all health workers recognise that they are involved in the care of leprosy-affected persons is the goal. He feels integration of diagnosis and treatment is a better use of limited resources.

The Indian programme has implemented its 5-year plan with the aim of further reducing the burden of leprosy. The WHO 'Global Strategy for further reducing the leprosy burden and sustaining leprosy control activities (2006–2010): operational guidelines' inform the programme and have been implemented successfully. It is hoped that the aim of reducing the leprosy burden will be facilitated by decentralisation with independent monitoring of the programme at the state level.

The programme aims at capacity building of health care staff in general and leprosy specifically. There is a focus on prevention of disability and reconstructive surgery.

The programme also aims to reduce stigma using information and education. The promotion of National Leprosy Day on 30th January will help to keep leprosy in the public

domain. It is also planned that activities involving leprosy-affected individuals will be held throughout the year.

The importance of good data collection and monitoring is central to an effective programme and Dr. Joshi outlined the way this will be ensured in India. Monitoring reports are sent by the states to the Ministry of Health in Delhi on a monthly basis and spot checks are carried out. ILEP partners provide feedback and WHO coordinators also send reports to the Ministry of Health. There are also cohort analyses of paucibacillary and multibacillary cases with respect to the successful completion of treatment.

The prevention of disability is a key function of the leprosy programme and it is hoped that this can be achieved using well-defined activities at the level of primary care such as diagnosis and management. This includes improvement in the management of complications and there are clear guidelines for the referral of complicated cases.

Individuals with disability will have access to reconstructive surgery which will be provided in secondary care facilities where possible. Reconstructive surgical services are viewed as particularly important in the drive for full integration. The Indian programme is also planning innovative financial incentives for people undergoing reconstructive surgery and the government institutions providing such services. It is envisaged that both the individuals and the institutions will be paid US\$150 for each procedure carried out. This initiative will be closely evaluated. Training in self-care for both leprosy-affected persons and village workers/volunteers is being implemented.

A major concern of leprosy workers is that with declining numbers of patients and a move towards full integration of health services, skills required to diagnose and care effectively for individuals with leprosy will be lost. Dr. Joshi hopes that in time training in leprosy will be performed at induction of all new staff and repeated on an annual basis. He believes that 'training is a continuous process'. Recognition of reactions and nerve damage is important and should be a skill possessed by all health workers from the village level worker to those working in health care centres.

The quality of training is a concern and efforts are being made to improve this. He hopes that task-orientated learning rather than didactic methods will become the norm. ILEP partners are helping to monitor this.

The ILC is fundamentally a research orientated conference and Dr. Joshi feels that research priorities are broad but from a leprosy programme perspective operational research is most important. Operational factors such as the quality of services, the skills of health workers, the incidence of nerve damage and stigma reduction all need to be monitored. It is especially important for health workers to be aware of the outcomes of their interventions.

The role of dermatologists was the topic of a special issue of *Leprosy Review* in March 2007 and Dr. Joshi feels that their role in the Indian context is very important. Policy is being developed to better define their role because as new case rates fall (or greater integration is achieved) it is likely that an increasing proportion of individuals will be diagnosed by dermatologists. He hopes to develop a central registration system for cases diagnosed by dermatologists.

Dr. Joshi also views dermatologists as a valuable educational resource. Their skills are also extremely valuable in reviewing the quality of programmes. He hopes to motivate dermatologists to be closely involved with the leprosy programme.

Dr. Joshi welcomed the ILC as an excellent meeting which emphasised partnerships and also allowed the sharing of information regarding programmatic systems.

Dr. Maria Leide was appointed manager of the National Leprosy Programme of Brazil in May 2007. This is the third time she has led the Brazilian government's leprosy campaign. She is Professor of Dermatology at the Universidade Federal do Rio de Janeiro. She has been interested in leprosy throughout her career, an interest which started as a medical student when she was involved in a research project involving armadillos.

Dr. Leide acknowledges that social factors, such as poverty, which are intimately related to leprosy are a challenge beyond the scope of the programme she leads. She also believes that lack of knowledge about leprosy within local communities is a major problem.

The Brazilian system of government of federal, state and municipal autonomy results in challenges which require the development of partnerships. She cites as an example that funds passed to states and municipalities for leprosy work can be redirected by these agencies to other areas of need. This requires advocacy on behalf of the programme and partnership between federal government and the states to ensure funds are used for leprosy work.

The Brazilian strategies for reducing the burden of leprosy are very similar to those outlined by Dr. Joshi. These include increased integration of services with a concomitant increase in the number of health posts. Dr. Leide acknowledges the need to improve strategies for the prevention of disability and that the registration of cases needs improvement along with the monitoring of operational quality indicators such as the percentage of patients cured.

The Brazilian National Programme has recognised that the percentage of patients with WHO Disability Grade 2 has remained constant at 6% of new cases for the last decade and has proved very difficult to reduce. Twenty three per cent of new cases require some form of care to prevent or treat disability. A central aim of the Brazilian National Plan for 2008–2011 is to reduce the total disability (both grades 1 and 2) by 30%. It is hoped this will be achievable with earlier diagnosis by improving coverage and local active case finding.

An innovative partnership with the diabetes programme to provide foot care and footwear to both leprosy-affected people and individuals with diabetes is working well and a good example of integration where services requiring common skills can be shared and better utilised.

In Brazil the training of staff in diagnosis and treatment is performed by the states. The Ministry of Health in partnership with ILEP members is involved in disability training. The states sometimes request the National Programme to help with training.

Dr. Leide is also initiating capacity-building workshops for managers in the most endemic areas to give them the skills to be able to evaluate local programmes themselves.

In association with the dermatological society of Brazil Dr. Leide has produced a leprosy module for dermatologists to use as part of a Continuing Medical Education programme. The development of an electronic educational tool for leprosy and skin disease to increase awareness of differential diagnoses may help to prevent misdiagnosis of conditions that are not leprosy.

Brazil has a high rate of leprosy in the under 15 age group and the programme is starting a validation exercise of the diagnosis of leprosy in this group in hyperendemic areas.

The research priorities outlined by Dr. Leide echoed those of her Indian counterpart in particular operational research to ensure the effective delivery of quality services. The National Programme in Brazil has two workshops planned for the first half of 2008 to develop affordable research initiatives at a local level.

As a dermatologist herself it is understandable that Dr. Leide would welcome greater involvement in leprosy issues from her dermatology colleagues but she recognises that

leprosy work is financially less rewarding than other areas of dermatological practice. Dermatologists undertake a large part of the diagnosis but few are involved in long term management.

She hopes that by encouraging informal links between state and municipal leprosy services and regional dermatology societies that increased levels of participation by dermatologists will ensue.

The most striking feature of the interviews with the National Leprosy Programme Managers from India and Brazil is the similarity in the approach to dealing with the burden of leprosy in their two countries. They both believe that political will is the overall driver of change in the improvement of services for those affected by leprosy. The two programmes are placing high priority on the maintenance and development of partnerships with other government agencies and non-governmental organisations. The Global Strategy is being implemented and the development and monitoring of innovative projects to reduce levels of disability are being fostered. Reassuringly they both recognise the need for continued research to improve our understanding of leprosy and the best way to manage the disease and its sequelae.

A recurrent theme throughout the ILC was the need to keep striving ‘towards a world without leprosy’ and not to allow complacency to develop in the wake of successes that have been achieved. The leaders of the National Programmes in the two countries with the largest burden of leprosy are going to try to meet the challenges of the next 5 years with the aid of a wide range of partners and by further integration of leprosy into general health services. They will act as advocates for their programmes and ensure that leprosy is kept on the health agendas of their governments. This is the best way to ensure that the best possible services are available for leprosy-affected individuals.

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