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REPORT OF THE JOINT ILEP/WHO WORKSHOP ON *REACHING UNDETECTED LEPROSY PATIENTS IN ENDEMIC COUNTRIES*

WHO Headquarters, Geneva, 26 June 1998

Fédération Internationale des Associations contre la Lèpre
International Federation of Anti-Leprosy Associations
Internationale Vereinigung der Leprahilfswerke

World Health Organisation
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1 Opening

Dr S.K. Noordeen, Director, Action Programme for the Elimination of Leprosy, WHO, welcomed all participants and he stressed the importance of this second joint ILEP/WHO workshop. He noted that by the year 2000, 1.5 million to 2 million new patients would have to be detected. Initiatives and innovative solutions are necessary to reach hidden patients and prevent disability in leprosy, and this meeting should provide the impetus and the means to achieve those goals.

Dr J-P Schenkelaars, President of ILEP stressed the good collaboration between WHO and ILEP, which will be given a new impetus by ILEP entering into Official Relations with WHO. He explained that the Federation was currently discussing a five-year strategic plan and was planning to build broad strategic alliances for the future. He reiterated the commitment of ILEP and its Members to the elimination of leprosy and he thanked the WHO/LEP team for the work they had put in when preparing this meeting.

2 Report of last meeting

Prof. M.F. Lechat, Chair of the WHO/LEAG and Co-Chair of the Workshop, stressed the importance of the workshop for increasing awareness and sustaining the interest in leprosy of all those concerned. He emphasised the value of the collaboration between WHO and ILEP, and of the ILEP Medico-Social Commission.

He reminded the participants that the fourth meeting of the Leprosy Elimination Advisory Group (LEAG) earlier in the week had recommended the strengthening of the partnership between all agencies, including national and international NGOs, as well as groups and associations of people affected by leprosy, with a view to achieving the goal of leprosy elimination and tackling the challenges that remain.

Prof. W.C.S. Smith, Chair of the ILEP Medico-Social Commission and Co-Chair of the Workshop, referred to the recommendations of the first workshop, held in July 1997:

1. In the effort to reach undetected cases, the primary health care system should be strengthened by:
   - Training all health care staff in diagnosis, treatment and care of patients, capacity building measures for local health workers to improve MDT services;
   - Involving other non-leprosy NGOs, local leaders, volunteers and their communities.
2. Initiatives and special campaigns like Leprosy Elimination Campaigns (LEC), Special Action Projects for Eliminating Leprosy (SAPEL), etc. should be implemented within the national leprosy programme, particularly in difficult areas. Particular emphasis should be given to sustainability on the completion of special actions:
   - All potential partners, technical and financial, should be involved starting from the early planning stages;
   - Special projects need not all be directed to WHO for funding but information regarding these activities should be reported to all parties concerned.
3. Encourage the wider use of leprosy elimination monitoring (LEM) to measure access to MDT and the success of the programme, using indicators of: drug supply, patient care and leprosy elimination.
4. Organise national leprosy campaigns involving, on a larger scale, local NGOs, media and politicians, well-known figures, as well as people affected by the disease to demonstrate that they can lead a normal life.
5. Improve information systems to identify areas needing attention, for example through the use of Geographic Information Systems (GIS).
6. The co-ordination of activities is essential. A regular meeting at the initiative of Governments with local and international agencies should be held at least annually.

7. In promoting collaboration and monitoring progress towards reaching undetected patients, a joint Workshop between ILEP, WHO and the National Programme Managers should be held once a year.

In Prof. Smith's opinion the recommendations are, to a large extent, being implemented. Joint work between ILEP and WHO has been strengthened in order to reach undetected patients in endemic countries.

3 Updates on the current situation regarding undetected patients

Dr D. Daumerie, of WHO/LEP, made a presentation on the current situation of undetected leprosy patients. Leprosy is under-reported: at the community level, it is not perceived as a disease in the early stages and is stigmatised at advanced stages; at the health service level, there is little involvement, poor coverage and it is, as a whole too complicated and not rewarding; at the political level: leprosy is given a low priority as it affects mainly marginal populations, and its control relies heavily on external funding.

There is no definite tool to measure the extent of leprosy. Estimates are based on a combination of factors: existing information, national information systems, surveys, campaigns and rumours.

Currently there is 1.5 to 2 million new patients to be detected and treated. This figure relates mainly to "at risk" patients likely to develop complications and likely to transmit the disease. These patients are the most difficult to access due to the absence of leprosy services, difficult local situations and lack of community awareness. This represents the largest part of the "backlog".

The majority of undetected cases live in major endemic countries. India includes the highest number (Assam, Bihar and Orissa), followed by Indonesia, Bangladesh, Cambodia, RD Congo, Guinea, Laos, Liberia, Madagascar, Nepal and Mozambique.

Dr Daumerie concluded his presentation by stating that the number of undetected leprosy patients is still unacceptably high. This will definitely compromise the reduction in disability risk, the decrease in disease transmission, the elimination at sub-national levels and the credibility of elimination programmes. This could be prevented by: increasing MDT service coverage, simplifying and integrating leprosy control activities, creating community awareness and organising national and local campaigns.

4 Main conclusions of a co-ordinating meeting of non-English-speaking countries of Africa

Dr Ji Baohong from the Association Française Raoul Follereau (AFRF) reported on a meeting organised jointly by the AFRF and WHO, last November in Abidjan, on the theme: *Dépister et traiter tous les cas de lèpre* (Towards the detection and treatment of all cases of leprosy).

The objectives of this meeting, targeted at the national leprosy co-ordinators of non-English speaking countries of Africa, were:

- Review the progress achieved towards the elimination target.
- Develop action plans for improving case-detection, increase the geographic coverage of MDT and ensure prevention of disability.
- Exchange information between the various programmes.
- Discuss the recommendations from the 7th WHO Expert Committee on Leprosy and their implication for elimination programmes.
- Harmonise the tools and directives for the implementation of MDT in all countries.

The situation of leprosy in this part of the world was reviewed. At the end of 1996, the registered prevalence in the WHO African region was 1.39 cases for 10 000 inhabitants, with the number of new cases remaining stable due to the expansion of MDT programmes and the detection of hidden and old cases.

The most important concern in non-English-speaking Africa remains the undetected cases. This is due to three main factors:

- Lack of information and awareness of the population, the patients and the health workers.
- Insufficient geographic coverage in most countries.
- Little integration and decentralisation of responsibilities in the existing elimination programmes.

Dr Ji concluded his report by stressing the positive aspect of the tripartite collaboration between AFRF, WHO and the National Leprosy Co-ordinators. Similar forms of collaboration exist in other parts of the world, notably in the American and the Pacific regions. It is essential that responsibilities are shared between the various partners and that intentions are transformed into actions. Dr Ji indicated that the AFRF is considering another meeting for all African national leprosy co-ordinators in the near future. The recommendations of the workshop have been published and are available on request.

5 Leprosy Elimination Campaigns (LECs)

Dr Myo Thet Htoon, of WHO/LEP, described how LECs were initiatives aiming at detecting leprosy cases, especially the "cases of consequence" that remain undetected in the community, and treating them with MDT. The LEC strategy is based on a combination of three elements: capacity building measures for local health workers, increase of community participation at peripheral levels and special efforts towards case-finding and treatment with MDT. A review of countries having carried out LEC activities has been done in 22 countries.

Dr Myo Thet Htoon concluded his presentation by stating that LECs are providing critical support to the national programmes by improving accessibility and community awareness, reducing the stigma, detecting many new cases, involving new partners, re-motivating health workers and increasing demand for services.

6 WHO-supported LECs in action

The respective national programme managers presented case studies from Ethiopia, India, Guinea, Madagascar, Myanmar and Nigeria.

Ethiopia: Dr. Wolde described the situation of the leprosy campaign in Ethiopia, which is a vertical programme, with a 100% MDT coverage. All regions still have a high prevalence, with a significant number of child patients. Progress has been made towards integration and combination with tuberculosis in four regions: Tigray, Oromiya, SNNPG and Amhara. The BBC MPM initiative feasibility study carried out in Ethiopia, to improve community awareness was well received by politicians. Oromiya and Amhara have been selected for implementing a LEC strategy.

India: Dr N.S. Dharmshaktu gave a comprehensive presentation on the situation of leprosy in India, which contributes to 58% of the world's recorded leprosy cases. In 1997 and 1998, under the auspices of the National Leprosy Eradication Programme, a Modified Leprosy Elimination Campaign (MLEC) was conducted in 21 states/territories in India, involving 800 000 health workers and volunteers. The strategy for the MLEC was based on the supply of IEC material and training to all health workers three months in advance, mass awareness campaigns, and extensive house-to-house search operations for a period of six days. The searches have led to the detection of 2 300 000 suspected leprosy cases, among whom 423 000 have been confirmed so far. This large-scale LEC was made possible thanks to a strong political commitment, the support of the health authorities and the local NGOs, the involvement of the community and the mobilisation of additional resources.

Guinea: Dr. A. Sherif, National Leprosy Co-ordinator, reported on the results of the LEC that has been implemented in Guinea in collaboration with WHO and the AFRF. The campaign which lasted around 2 months has allowed the detection of 6 117 new cases in 1997 against 3 200 in 1996. In addition, 2 600 villages have been visited by 2 700 community workers.

Madagascar: Dr Mamy Ralamboson, National Leprosy Co-ordinator, after describing the exceptional problem of access prevailing in Madagascar, presented the results of the LEC campaigns which started in 1997 and have been expanded in 1998. The LEC was started in April 1997 in 14 districts of the East Coast, covering a population of 2.27 million living in 1 725 villages. The campaign which was conducted over a period of 6 months detected 6 810 cases. Because of the LEC the annual case detection for the country in 1997 reached 11 555 compared to only 3 921 new cases detected in 1996. MDT is now available in all health centres and the stigma has been greatly reduced. Dr Ralamboson concluded by stressing that such impressive results have been obtained thanks to the commitment of the various actors, the improvement of logistics and the involvement of the community.

Myanmar: Dr Kyaw Nyunt Sein made a progress report on the Leprosy Elimination Campaigns, which have been carried out in Myanmar in 1997 and 1998. LEC teams have been formed in six hyper-endemic regions where MDT was first started, and townships have been selected according to the WHO guidelines. Villages are selected on the basis of epidemiological and operational data, as well as on information from local health staff and community leaders. Innovative approaches are used to implement the campaigns. This includes advocacy meetings in order to obtain political commitment, training of basic health staff, recruitment of volunteers and intensive use of media. So far 20 LEC teams including one self-supporting LEC in Mandalay Division have been organised. 3 410 new cases have been detected in 2 821 villages. Dr Kyaw Nyunt Sein concluded by stating that the LECs have been very successful thanks to the commitment of the National Government and local authorities and the involvement of local NGOs and volunteers.

Nigeria: Dr Sofola reported that, at the end of 1997, there were 12 878 patients on register in Nigeria. The disability rate among new cases was 15% whilst the proportion of MB cases was 72%. The geographical coverage being low, it was felt that there were many hidden cases in the country. To address this problem, LEC campaigns were started in three states (3 in Enugu/Eboyi, 4 in Benue and 4 in Ondo States). The activities carried out during the LECs can be grouped into advocacy visits, increasing community awareness, capacity building and case finding/treatment. A population of 236 409 villagers was screened in 978 villages. The number of new cases detected during the two months of case-finding was 1012. A total of 404 local health workers and 580 volunteers were trained during the campaigns, thus improving accessibility of MDT services to patients. In conclusion, Dr Sofola stressed the benefits of LECs and indicated that they will be continued in other selected areas.

Nepal: Dr J-P Baral reported on the two LECs programmes which have been implemented in Nepal, one near to the border with India and the other one in the Mid-Western Region. Both regions are difficult to access. He reported how LECs have been positive in providing good incentive to NLP staff and officials, sustaining leprosy activities at peripheral level, increasing coverage of MDT services as well as public awareness, and reducing stigma.

7 The example of Bihar/India: support to leprosy control activities through technical teams

Dr Etienne Declercq presented an initiative carried out by the Damien Foundation India Trust (DFIT) in the State of Bihar, which contributes to about 10% of the global leprosy case load worldwide. In order to remedy the lack of technical expertise, it was decided to introduce technical teams at district level in 15 districts. Each team consisted of a Medical Officer and a Supervisor with extensive experience. Their role was to support the NLEP staff in planning, organising, implementing, monitoring and evaluating the leprosy programme as per the Government of India guidelines. In all, DFIT had 10 Medical Officers and 13 supervisors covering 15 districts.

The total population screened in the districts was 39 547 000 (42% of the State). In the 15 districts, 43 498 new cases were detected in 1996 and 62 629 in 1997.

The programme has been very successful, although problems arose with regards to staffing, transportation, access and political commitment. The DFIT programme in Bihar is co-sponsored by NSL and the Government of Belgium.

In the discussion which followed the presentations three major points were highlighted:

a) The good results of LEC activities should be widely publicised so that partners can increase their commitment and sense of ownership.
b) LECs should be developed from the early stages with all partners. Early discussions are important if LECs are to succeed.
c) The resources, which we have today, should be used in the most collaborative way. Opportunities cannot be kept waiting.

8 BBC MPM Initiative on IEC activities in selected countries

Mr Roy Head reported that, at the request of the WHO's Action Programme for the Elimination of Leprosy, BBC MPM has completed a five-month feasibility study, planning a media campaign to dramatically accelerate the elimination of leprosy as a public health problem. Five of the world's most leprosy-endemic countries were visited: India, Brazil, Indonesia, Nepal and Ethiopia. The BBC MPM team spent a total of 11 weeks in the field, negotiating with both governments and media organisations. These negotiations have proved to be very successful. A report was given on the feasibility studies and proposals for the media campaigns were explained. All elements are in place and are simply waiting to be activated. Potential partners have made some quite remarkable offers, agreements have been reached and, with the possible exception of Indonesia, governments and media in every country are impatiently waiting for the campaign to start. All that remains is to secure the necessary financing. He emphasised the need to move swiftly if the momentum built up so far was not to be lost.

9 What is SAPEL (Special Action Projects for the Elimination of Leprosy)?

Dr G Cabanos of LEP/HQ recalled that SAPELs are initiatives aimed at providing MDT services to patients living in special difficult-to-access areas or situations, or to those belonging to neglected population groups. They seek to address the problem of inequity in health care. 61 projects in 26 countries have been implemented. Parameters are being developed to evaluate the success of the projects. This is being done in conjunction with partners and within the national plans for elimination.

10 SAPEL in action (case studies from Bangladesh, Brazil, Indonesia, Philippines, Sudan and Yemen)

Bangladesh: Dr Ahsan Ali reported on a SAPEL project that was started in one district of the Rangamati District of Chittagong Hill Tracts. The main strategy was to implement MDT through village volunteers from the local population, who were provided with basic training in leprosy. The salient features of the plan of action consisted firstly of meetings with local leaders, then recruitment and training of village level volunteers, activities by volunteers, and finally supervision and monitoring of the programme. Difficulties arose in the carrying-out of the programme, due to weak infrastructure, hostilities and natural disasters. 1 210 villages were visited, covering a population of 401 400; 19 new cases were detected.

Brazil: Dr M Leide Wan-Del Rey de Oliveira reported on the SAPEL projects which have been implemented in the Amazonas Region, and also on two urban programmes started in Rio de Janeiro municipality. She stated that more SAPELs are planned in the Northeast region in the near future.

Indonesia: Dr Yamin Hasibuan described the situation of leprosy in Indonesia. There are 28 088 registered patients who are very unevenly distributed, reflecting the complex topography of the country. In order to reach patients in difficult areas, two SAPELs have been conducted, one in Yapen Waropen district of Irian Jaya Province and the other one in Kepulauan Riau district of Riau Province. The activities undertaken consisted of orientation training in leprosy for the HC doctors and paramedical workers, orientation training in leprosy for community

members, and case finding by HC workers and community leaders. 67 leprosy patients were detected between June 1996 and September 1997. Community participation was encouraged to help patients in the villages. The SAPEL project has enhanced the knowledge of people in regard to leprosy. Four more districts are listed to be put on SAPEL projects.

Philippines: Dr J. Abella gave a presentation on a SAPEL programme, which has been implemented in Abra, which is a landlocked province, most of which is mountainous. Most of the 27 towns are not accessible by ordinary land transportation half of the year. The population is 200 348. The SAPEL programme started in June 1996, after consultation with the local health authorities and the involvement of the community health workers and midwives. 43 new cases were found from June 1996 to May 1997. Dr Abella concluded that, although the number of cases detected has been smaller than expected, the exercise has provided other gains in term of motivation of the staff and awareness of the population.

Sudan: Dr El Fatih El Badawi reported on the situation of leprosy in Sudan. Leprosy is endemic in the South and the West, with an estimated number of 20 000 cases in the South. The number of registered patients by the end of 1997 amounts to 6 588. The implementation of MDT is difficult due to the geographical situation, insecurity and civil war. Six SAPEL projects have been implemented in Sudan, four have had successful results and two have been delayed due to the difficult situation. The six SAPELs covered a population of 845 000 and 1331 new cases were detected. Mobile teams and community leaders were used to implement the projects. There was a strong commitment from local government and the involvement of local NGOs in the project.

Yemen: Dr Yasin Al-Qubati described the situation of leprosy control in Yemen. In spite of the existence of a good national leprosy control programme, there are some areas, which remained out of reach due to security problems and the difficult geographical nature of the country. SAPEL activities were planned and carried out in order to reach the hard-to-reach populations. Three SAPELs (Sayhoot, Thamood and Al-Saeeid) have been implemented, covering a population of 458 865. About 250 new cases have been detected. The main activities of the programme consisted of public health education, surveys, new clinics and training of health workers. There was a good collaboration between the various partners - NGOs and related health agencies. Difficulties arose due to scattered population, very high social stigma, security problems and competition with other diseases. The three SAPELs will now become part of the NLCP routine activities, which intensify the importance of SAPEL in increasing the geographical coverage in Yemen.

11 ILEP presentation on recent experiences in case-detection activities

Mr Trevor Durston, General Director, The Leprosy Mission International, explained how the mission has developed different models in India in order to tackle the problem of case-detection. He retraced the main features of three models and the lessons learnt.

AMPLE Programme
The accelerated MDT programme for leprosy elimination (AMPLE) was initiated in 1992 in some districts in the states of West Bengal, Bihar, Uttar Pradesh and Madhya Pradesh in collaboration with the local government authorities. District teams comprising one doctor, two non-medical supervisors, a lab technician and other PMWs carried out rapid chase surveys and cover the district in about 3-4 months. Village leaders were involved and messages on leprosy were broadcast using loudspeakers. The teams also visited clinics in the areas, worked with local staff and were able to review the registers. Since beginning the programme 28 districts have been covered, including three districts in the state of Bihar. The population covered by all these programmes is in excess of 63 million. A total of 53,911 suspect cases were screened, out of which 33,847 new cases were detected.

EMPROS Programme
The enhanced MDT programme by rapid organised survey (EMPROS) was introduced in 1994 as a twelve-month programme suitable for key districts in Bihar. Teams working under a district supervisor consisting of two non-medical supervisors, up to 24 PMWs, and a lab technician visited all houses in the area. PMWs working in teams of two would talk to family

members about MDT treatment and the early signs and symptoms of leprosy. Examinations would be carried out on the spot for people with signs of leprosy. Registers in the clinics were thoroughly reviewed. Female schoolteachers and about 100 female volunteers were involved in the programme. During the twelve-month programme a population of 1.3 million was covered in one district in Bihar, and 4,557 new cases were detected. In spite of the success of new case detection, this programme required a very heavy commitment of staff time when compared to other methods, and was therefore not repeated in other districts.

Gender Study Programme

TLMI had been concerned that earlier models of case detection had not been able to significantly reach the female population. A special study was set up in five centres by using female workers and volunteers. The teams worked very closely with the concerned development officer of the block being covered, and also by contacting village leaders. The activities included intensive house-to-house surveys together with health education programmes organised in each village. These health education programmes were extended to schools and colleges in the area. In the five centres a total of 1.25 million population was covered. Of this population 632,000 were male and 625,000 were female. This study confirmed the advantage of working with a high proportion of female workers in the PMW teams, and also showed that, in areas where TLMI's control work has been long established intensive house-to-house surveys will still uncover large numbers of new cases.

Mr Trevor Durston concluded that different models of case detection need to be applied selectively to the areas where they are most effective. When making this selection, the factors which need to be taken into account are the endemicity of the area, the disability rate among new cases, the effectiveness of the existing leprosy programme in the area, and cultural factors especially those relating to women's issues.

12 Improving the sustainability of leprosy activities/capacity building of programmes

Dr Henk Eggens described how leprosy services were changing in many parts of the world and how there was a need to review their organisation and make them more sustainable over time, with a minimum of external input and sufficient human resources to deliver the services.

In spite of all the progress achieved over the past fifteen years due to the introduction of MDT a number of concerns remain that justify the continuation of leprosy services for a number of years. New cases continue to appear and are in need of MDT and other services and there is a need to address the physical and socio-economic complications of leprosy and the changing context in which health services are operating, notably because of health sector reforms. These structural changes have wide implications for leprosy services that need to be addressed when drawing up new strategies for sustainable leprosy services.

An overriding question is what kind of leprosy services will be needed in future. A second question is whether the existing services are adequate to respond to the service objectives that have been defined. Sustainability will depend on the resources available to services. Apart from the necessary financial resources, sustainability will depend heavily upon the capacity to maintain an adequate level of expertise in the field of leprosy. A situational analysis of the leprosy problem and the available resources will have to be made and changes carefully planned and implemented, including all stakeholders in the process.

Dr Eggens described some initiatives of ILEP with regards to sustainability. In September 1996 a workshop was organised by the Medico-social Commission in Amsterdam, which developed some guidelines for assisting national programmes. A workshop was organised in Vietnam in May 1998 to review the situation and promote the process for an increased sustainability of health services in the country.

He concluded that sustainability was an issue that needed to be addressed today and that a careful stakeholder analysis may reveal considerable opposition to implementing measures aimed at enhancing sustainability.

13 Workshop recommendations

Since the last Workshop in July 1997, the progress made in reaching the undetected patients in endemic countries has been substantial. However, efforts in this direction should be pursued further through LECs, SAPELs and other special initiatives. More emphasis should be put on the actual implementation of field activities and not only on sharing of information and intentions. It is hoped that this joint ILEP/WHO meeting will send a clear message to the field for the strengthening of collaboration and improvements in the implementation of leprosy elimination activities.

While this second Workshop endorses the recommendations of the first Workshop, particular emphasis is placed on the following:

a) The *special initiatives* should ensure that all the patients detected are treated and cured. In addition, national programmes should ensure that leprosy activities are sustained.
b) The *special initiatives* should be based on good collaboration between national programmes and their various partners.
c) The *special initiatives* should see the involvement, especially in the initial phases, of all partners so as to increase "ownership" and appropriate support.
d) The *special initiatives* should be subjected to adequate evaluation so as to benefit future efforts in this direction.
e) There is considerable scope to mount co-ordinated national and international media campaigns to promote detection of undetected cases. All partners should promote and support such activities.
f) Information on *special initiatives* should be widely circulated, especially to NGOs, so as to strengthen support.
g) *Special initiatives* should involve, as much as possible, local authorities, community leaders and other relevant bodies.

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*** Invited but unable to attend**