



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

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9th Meeting of the ILEP Technical Commission

Wednesday 19 September 2007

London, United Kingdom

MINUTES

In the Chair: Dr Pieter Feenstra (PF)

Present: Dr Guido Groenen (GG), Prof Baohong Ji (BJ), Dr Padebattu Krishnamurthy (PK), Dr Ernst Hisch (EH), Dr Paul Saunderson (PS), Dr Myo Thet Htoon (MH) *WHO Global Leprosy Programme*, Mr Douglas Soutar (DS), Mr Andrew Clark (AC), Ms Imogen Prickett (IP)

Apologies: Prof Diana Lockwood (DL) Dr Montserrat Pérez (MP)

1. Approval of Agenda

The agenda was approved with the following additional agenda items added:

- 4.3 Report on the WHO/DAR Meeting (DS)
- 12.1 Dapsone sensitivity (PS)
- 12.2 International Leprosy Congress

2. Points Arising from the Minutes of the Previous Meeting

No points were raised.

3. POD

3.1 It was reported that Learning Guide 4 has now been translated into French and Spanish. These versions are available to download from the ILEP website and have been included in the CD of ILEP Technical Publications. AIFO and GLRA, the Language Coordinators for Portuguese-speaking Africa and Brazil, have been contacted to ascertain the level of need for a Portuguese version of the Guide.

4. CBR

4.1 EH reported that there have been no further meetings of the TEG CBR. He presented the 'Toolbox for Impact Monitoring and Evaluation of Savings and Credit Programmes' and the 'Report on the Savings and Credit Programme of NGO-IDEAS Partner Organisations'. These have been developed by NGO-IDEAS, which is a partnership between 14 German and 32 Indian NGOs. The project will be extended next year.

Action: EH will draft a handover report on the activities and progress of the TEG CBR for the information of the next ITC. EH will send a copy of the Report and Toolbox to each of the members of the TEG CBR for their comments. A copy will also be sent to the member of the next ITC who is elected under the CBR cluster.

4.2 The CBR Technical Guide is now in the final stages of technical editing with WHO. WHO will allocate an ISBN number and ILEP will be responsible for the printing process. The ILEP Secretariat and WHO are currently working closely together to finalise the process which is expected to be completed by the end of 2007. It will be available in electronic format for the ILC in January next year.

Members noted that although the process of producing this Technical Guide in collaboration with WHO has taken time and highlighted some challenging bureaucracy, much has been learnt. It is anticipated that future collaboration on publications will be an easier and more streamlined process.

Action: The Secretariat will continue work with WHO on the printing of the CBR Guide.

4.3 DS reported on his attendance at the WHO/DAR partners meeting recently in Geneva. The meeting focussed on the DAR Action Plan 2006 - 2011, in the context of the UN Convention on the Rights of People with Disability. ILEP was invited to attend the meeting as a result of our increasing collaboration with WHO and contributions made to DAR activities. DS recommended that the new ITC be requested to consider the most appropriate ways to engage with DAR in helping to implement their Action Plan. He also recommended that ILEP Members encourage networks of leprosy-affected peoples to network more widely with Disabled People's Organisations. This was felt to be particularly important in terms of promoting effective implementation of the UN Convention.

The recent emails from Dr V Pannikar (WHO) and Dr S Deepak (AIFO) posted on the Noto Mailing List, regarding strategies for rehabilitation of people affected by leprosy, were also discussed. Dr Pannikar wrote: 'If experts concerned with the welfare of people affected by leprosy are serious and if our objectives are clear, then it is possible that we can launch on a rehabilitation strategy which will be integrated within the broader efforts to improve quality of life of all socially marginalised members of the community in a very positive way. I believe that chances of success for an exclusive leprosy-centred rehabilitation strategy will be very limited'.

Action: The ITC endorses Dr Pannikar's statement on rehabilitation and the ILEP General Secretary's recommendations following the DAR meeting.

5. Health Education/IEC

5.1 PS's paper entitled 'Evaluating Health Promotion Activities: a selective, annotated bibliography' has been added to Technical Bulletin #13. This has been translated into French, Portuguese and Spanish and uploaded to the ILEP website.

6. Training Teaching and Learning Materials

6.1 The Grid of Essential Texts was discussed. DL drafted a list of all major medical textbooks (e.g. The Oxford Dictionary of Medicine, and major textbooks on infectious

diseases) that include a chapter on leprosy, and these were added to the Grid with reference to the appropriate chapter/section.

The inclusion of chapter references into the Grid has increased the size and made it unwieldy. It was agreed that all specific chapter references should be removed from the Grid, with a reference only to 'Chapters/Sections in Medical Textbooks', in the 'Programme manager', 'Medical specialist' and 'General medical doctor' rows. This reference should be linked to a table providing more detailed information on each publication.

It was noted that this document is not solely an ILEP product, and should therefore be referred to as the 'Grid of Essential Texts', with no reference to ILEP.

Action: IP will update the Grid according to the directions from the ITC and work to improve the format for ease of reading/printing on the ILEP website.

7. Issues related to collaboration between ILEP and WHO

7.1 MH reported on the progress made in the organisation of the next WHO TAG meeting which will take place in Bagan, Myanmar. Invitations to the meeting have been sent out. DS and PF will be attending along with the new ITC Chair, who will be appointed at the Board Meeting on Friday 21 September. This will create some continuity between the outgoing and ingoing ITCs. DS and the new ITC Chair will be able to feed back to the new ITC any important issues coming out of the TAG meeting.

Note: This meeting was cancelled due to 'unavoidable circumstances'. It will be rescheduled for March 2008.

7.2 There was some discussion on the collection and reporting of the WHO data. MH reported that the data will be updated in November as data comes in from more countries.

Members also discussed the analysis and interpretation of the WHO data. It was agreed that it is important for the ITC to provide analysis and interpretation of the WHO figures based on knowledge of the situation on the ground. This requires input from local staff as they are in a much better position to understand the real situation on the ground in each particular context. This is part of ILEP's focus on quality in leprosy services and data. Sentinel surveillance centres are suggested as a way to gather micro-data in order to develop a better picture of what is happening in a particular country. For example, it is possible to gather useful information on cure rates on a sample basis. The sentinel centres should be promoted in National Programmes, as a collaborative effort between WHO and ILEP.

Action: The issue of 'sentinel centres for surveillance of data' will be followed up at the TAG meeting and presented to the next ITC as an issue for their attention.

8. Meetings Update

8.1 MH reported on the progress made in developing training modules for the WHO Operational Guidelines. NLR/ GLRA/WHO developed modules are now in their third draft. Pilot training courses will take place in Ethiopia, with 11 countries invited. Five courses will be held in 2008. MH noted that the second draft of the training modules

was shared with the ITC and comments were received. NLR are in favour of this being an ILEP endorsed project and the issue will be raised at the cooperation meetings on the same day as this meeting.

9. Temporary Expert Groups

The Commission read and heard reports on the progress of the TEG on Information (ILEP/Infolep), and the TEG on Data and Data Collection.

9.1 The TEG on Information (ILEP/Infolep) includes staff from the Secretariat, from NLR (Infolep hosts) and an ITC representative (PS). The group have met three times in 2007. Since the last ITC meeting, the Brighton-based web-design company Liquid Light has been contracted to work on the design of the new website.

The development of a new resource library/database to update the current Infolep library is a process that will be slightly separate, but run in parallel with the development of the new website. It was agreed that the new database should be kept as simple and user-friendly as possible. The group will find some suitable software packages and work with Liquid Light to identify the best solution.

Following an initial planning workshop, Liquid Light is now drafting a schedule for development of the website and will work on some initial design swatches to present to the group at the next meeting.

9.2 The TEG on Data and Data Collection has been engaged in looking at ILEP's data collection questionnaires. Revised A and B Questionnaires were developed by the TEG and discussed by the group. The aim is to avoid collecting the same data twice, now that we are using WHO data as the authoritative epidemiological data. ILEP questionnaires should be used to collect data at a Federation level which will give a good overall picture of the activities of the ILEP Members. The ITC recognises that the revised questionnaires are products of a consensus reached within the group and agree with those on the condition that they are field tested. The data should not be collected through national Health Management Information Systems.

It was agreed that the Questionnaires should be renamed to avoid confusion with previous incarnations of the A and B forms. The Questionnaires should be renamed as follows, with the suggested subtitles remaining the same:

Questionnaire A: ILEP Project Profile Form

Questionnaire B: ILEP Annual Project Report

Question 301 on the B form should include references to households being specifically those affected by leprosy.

Action: The ITC have discussed the results of the work of the TEG and made some minor amendments to the revised questionnaires. The ITC recommends that they should be field-tested for at least one year by all ILEP projects, after which they will be reviewed.

In addition, a brief questionnaire should be given to programme managers about their thoughts and experiences of using the new questionnaires.

10. ITC Working Documents

10.1 The ITC has completed all activities in the Work Plan and the narrative-form Programme of Works, except for the CBR Technical Guide, which has yet to be completed. Some activities are ongoing but on schedule. Many of the activities of the ITC have served as input into the WHO Operational Guidelines.

11. Issue relating to the new ITC: appointment procedure, handover, pending issues etc

11. 1 Members discussed the contents of the induction pack which will be compiled for the members of the new ITC. The list of suggested contents was accepted, with the addition of the briefing paper on the progress of the CBR TEG.

12. Other Issues

12.1 Dapsone Sensitivity

PS reported that in Nepal, there have been recent accounts of serious reactions to Dapsone (Stevens-Johnson Syndrome), including liver disease. This is very rarely reported in Africa. Dapsone is not a vital ingredient in MDT and could therefore be withdrawn if there is risk of serious illness or death. The issue was referred to the new ITC for further discussion and advice.

12.2 International Leprosy Congress

DL had written reporting that the organisation and planning for the ILC has been inadequate, and Dr Noordeen's poor health has placed the event in jeopardy. She requested that ITC/ILEP consider what it might do to address the situation. The ITC agreed it should not try to take responsibility for the Congress, since the organisation of the ILC is the responsibility of the ILA. Moreover, this could have implications financially and politically for ILEP.

13. Closing Remarks

As this was the final meeting of the outgoing ITC, the Chair and Secretary thanked the members for their valuable contribution to the work of the Commission over the past four years.

Acronyms used in this report:

AFRF: Association Française Raoul Follereau
 AIFO: Associazione Italiana Amici di Raoul Follereau
 CBR: Community Based Rehabilitation
 DAR: Disability and Rehabilitation (a unit of WHO)
 GLRA: German Leprosy Relief and Tuberculosis Association
 ISBN: International Standard Book Number
 IEC: Information Education Communication
 ILA: International Leprosy Association
 ILC: International Leprosy Congress
 ILEP: International Federation of Anti-Leprosy Associations
 ITC: ILEP Technical Commission
 MDT: Multi Drug Therapy
 NLR: Netherlands Leprosy Relief
 POD: Prevention of Disability
 TAG: Technical Advisory Group (WHO)
 TEG: Technical Expert Group
 WHO: World Health Organisation