ILEP Members’ Assembly
Colchester, 20\textsuperscript{th} March 2018

Annex: 5 – ILEP Country Coordination Discussion Paper

Expected outcome of the session:

Discussion of potential directions to enhance country coordination

Identification of next steps leading up to October 2018 Members’ Assembly

Background documents included:

1. Guiding principles for ILEP Country Coordination (Approved by MA in March 2017)
2. Guidelines on Coordination and Cooperation at country level (Approved by GA in June 1995)
ILEP Country Coordination Discussion Paper

The aim of this work document is not to write another paper on coordination. Its sole purpose is to pave the way to revisit and revitalize any ILEP coordination. Why we need it? How can we implement it? What are the conditions for being successful?

Why was ILEP set up?

Because there was a common commitment that as a group of members, we could better use the available resources to the best possible effect (impact), providing quality services to persons affected by leprosy, avoiding duplication, and limiting gaps.

Yet, each member also has its own specificities, often wants to act with full autonomy, there are sometimes divergences of views, and occasionally even friction between members.

A sound balance

There is a need to balance these 2 realities, but there are also a number of other realities that we need to consider.

- **National programmes are increasingly taking leadership roles.** Several decades ago it was possible for members to operate without necessarily referring to the local authorities (Ministry of Health, National Leprosy Programme, etc.). But times have changed and those authorities now want to lead the process and to own the full package of policies related to leprosy in their country.

  There are clear indications that local governments will continue to increase their inputs in the fight against leprosy, and in health and development in general. Some countries that 25 years ago strongly needed outside support can now assign the required and skilled human resources and to generate and allocate enough funds for carrying out the essential activities. However many countries, especially in Africa, are still dependent of donors for sustaining their leprosy programme. But let’s be sure that there will be an evolution in these countries too.

- **Collaboration involves capacity building.** ILEP members are organizations with the aim to helping local partners to become technically autonomous. Transferring knowledge is not something that can be achieved quickly; it takes time for capacity building. In addition the emphasis of work has shifted. A few decades ago the focus was put on detection and treatment, later on prevention of disabilities and physical rehabilitation, but now increasingly, social inclusion and empowerment of persons affected by leprosy are a key focus. These changes were possible thanks to the development of a new therapy, the better understanding and management of nerves’ functions, the acknowledgement that nothing fully efficient could be achieved without involving the beneficiaries in tackling the disease and its social and cultural burden.

- **The new Global Partnership has considerable implications.** Again ILEP members are at a new turning point with the Global Partnership for Zero Leprosy. The future will tell us how we will be able to adapt to it. Is it an opportunity or a threat for the ILEP members? How will the Partnership influence our work in endemic countries? What will be the implications for coordination and collaboration in countries? The first half of 2018 might be critical.
• **Our growing engagement with other NTDs and related organisations will have considerable implications.** ILEP members are also at another turning point since a few years with the shift in focus towards neglected tropical diseases. The possibility of also having coordination mechanisms among the NTDs community would be a fantastic asset. Can we bring a valid model that works effectively?

• **ILEP members are not the only NGOs involved in the fight against leprosy.** There are other national and international organizations (e.g. Ordre de Malte, IDEA, ILA, Handa, Humanity & Inclusion -former Handicap International-, groups of Persons Affected by Leprosy, and Disabled Persons Associations) that provide several services to persons affected by leprosy. ILEP members can’t simply ignore them; we have to work with them, as often they reach the beneficiaries through expertise that we don’t always master.

Balancing all those aspects is not only a matter of paramount importance, but also a difficult exercise. Strong and efficient coordination will definitely be a key factor to achieve success in reaching our goals, requiring effective synergies and complementarities, mobilization of leverages.

Nevertheless, the ice has to be broken and sources of past disappointment about coordination among ILEP members have to be overcome. Coordination is not just a faraway hope. Coordination reflects what we are and what we want to do together: there must be a will.

**Consensus**

There have already been several editions to the “Guide of the Co-ordination of projects between ILEP Member-Associations” (1991, 1995, and later revisions). The last one being “Guiding principles for ILEP country coordination” drafted by an ILEP task group in 2017. The regulations and guidelines they include have been endorsed by different general assemblies. Despite this, after so many years, coordination remains a problem, a sensitive issue. If the ILEP CEOs globally accept these guidelines it looks that their field implementation does not meet the expectations. The causes are well know; there is no need to come back on them, one has just to read for instance an ILEP document issued by ILEP on 22 June 1995 (see scanned copy).

Even if there have been changes since then, a few fundamental questions are still in front of us.

• To what extent are we willing to prioritise the goal of working effectively together considering the differing technical expertise and financial capacities of each member?
• How far are we willing to integrate our actions within national leprosy programmes? (Are we “behind them” or operating in parallel?)
• How far are we willing to build up local capacities and change the paradigm “north-south” (switching the poles)?
• To what extent are we willing to emphasise, support and foster an increasing leadership role of persons affected by leprosy in our collaboration and coordination?
• To what extent are we willing for the priorities of the new Global Partnership for Zero Leprosy to have an influential role in our collaboration and coordination?
• These questions are not exhaustive, there may be more.

Leaving no one behind in the 3 components of the ILEP triple 0 strategy is a very nice goal. Sound coordination is a tool to achieve it. However, as long as ILEP members are not transparent in answering
the fundamental questions, as long as ILEP members are not unified, having the same vision, speaking
with the same voice, sharing the same message, we are doomed to fail. Our attempts at coordination
will not be credible if ILEP members do not reach a consensus from the very beginning. It’s not
acceptable to have 14 agendas: the only way through is to have a common agenda.

Effective coordination can only be developed and established under the condition that this consensus is
reached among all ILEP members, and that each member adheres to it, makes it known to its field
projects, and asks for its full implementation.

**Change of perspective**

Usually we consider these issues from our point of view as ILEP members. However, what if I was a
director of a national leprosy programme (or someone from the Ministry of Health in charge of NTDs).
Probably I would ask myself:

- What do I know about ILEP? -But do I know something?-
- What are the ILEP members, as other organizations, involved in leprosy control in my country?
- I’ve heard of an ILEP coordination but what is it in fact?
- Where can I find reliable information?
- There are indeed several ILEP members active in my country but it looks like that they do not
  form a block. So, can I succeed in funding my programme in approaching them individually?
- There is an ILEP member in my country (maybe more than one) but what can I expect from it?

These are some questions that a programme director can ask him/herself, but to the same could also be
true of others from different groups (e.g. organisations of persons affected, universities, donor
agencies).

It’s difficult to imagine effective coordination happening if someone like this programme director can’t
find the right answers to his/her questions. Likewise, it is unlikely that a donor agency would embark on
funding us if reliable information about coordination can’t be easily gathered.

One of the access points for this kind of information is the ILEP website. Are we sure it is complete,
updated? The information that can be found on this website is only a tributary to what each member
feeds to Geneva. For the time being (March 2018) there are quite a lot of discrepancies in this
information.

Each member should be invited to look in detail at all information relating to that organization on the
ILEP website. They should communicate by 30 June 2018 all wrong, obsolete, or missing information.
Then, once a year (1 October), the ILEP Office should ask members to submit an update by 31
December, with a reminder on 1 December.

**After this initial step**

To convince ourselves that we can contribute to a “good” coordination, ILEP members should share
some best practices, true case stories that show evidence that concrete goals can be achieved when
working together. We are 14 members within ILEP, let’s communicate 14 outstanding examples of
coordination (1 per member) in the past 3 years by 31 August 2018. It is not absolutely necessary to
explain best practices with other ILEP members, we can have nice examples of coordination realized
The strategic plans

The ILEP Office has already helped in facilitating the development of 10 country plans (among them 4 still have to be approved). A few more plans are in the pipeline. That’s a great job done with the participation of many: national leprosy programmes, WHO, ILEP members, NGOs that are not members of ILEP, etc. It would be useful to list those plans and post them on the ILEP website in an electronic version.

It is important that all participants have a sense of ownership of these plans. Otherwise there is a great risk that they will be put aside in a dusty drawer. In consultation with the National Leprosy Programme, the ILEP coordinator in each of the country where such a plan exists, must ensure that these plans are followed, monitored and evaluated. Similarly the ILEP coordinator must also ensure whether these plans are effectively linked to the ILEP strategy (or to the WHO leprosy strategy or to the Global Partnership for Zero Leprosy strategy in a few months).

Sustaining leprosy expertise

Sustaining leprosy expertise is not an easy task when in a country the disease is totally forgotten by the health authorities, or simply absorbed within the package of NTDs or integrated in general health services. Now, more than ever, we are at the brink of losing leprosy expertise. A generation of skillful leprosy health care workers has already retired or will retire soon and there are too few newcomers that are willing to embark their careers in leprosy control.

Here again coordination will have to play a substantial role. Country by country, our coordination must include a plan for attracting motivated HCWs, developing their expertise through targeted training, and consolidating their skills through exposure and practical experience. In principle this is something that should be included in broad lines in the strategic plans when available. Each member in charge of the coordination in a specific country must help the National Leprosy Programme to develop (or fine tune) such a plan for sustaining leprosy expertise, with a clear roadmap based on true needs, including a realistic assessment of the resources that have to be mobilized.

Sometimes the ILEP coordinator has to remind the national (local) authorities that leprosy still exists and requires a higher focus from them. The other members active in this country must also take any opportunity to enhance this statement from the coordinator.

An ILEP coordination structure

ILEP coordination starts with a strong commitment of member CEOs. Such commitment must be endorsed and followed by a comprehensive and transparent exchange of information between the project desks of the head offices. We can’t assume it will happen satisfactorily on its own within a specific country without being sure that this is in place. Nice declarations are not enough.

It is advisable to think of setting up a sort of ILEP coordination structure that would meet before a members’ assembly for a day twice a year. The coordination within 1 or 2 countries could be assessed per half day, depending on the complexity. Therefore, the number of concerned countries might range from 4 (minimum) to 8 (maximum) per year. These meetings should be attended by CEOs, directors of
project desks, and project managers (of the head office and/or of the representative office) as per the assessed country. According to needs, the director of the National Leprosy Programme (or its representative) might also be invited.

ILEP members can also for sure, initiate between them such meeting at any time should the need be raised.

**Types of ILEP coordination**

- Several (2 or more) ILEP members are active in a particular country, with or without representative offices
  
  This type of coordination is frequent, especially in countries where there is still a significant caseload. The principles of coordination are extensively described in “Guiding principles for ILEP country coordination”. There is no need to reinvent the wheel: the essential is inside. Read it, work on it, share it, implement it!

- One ILEP member is active in a particular country, with or without representative offices
  
  It should be considered that this ILEP member acts automatically as the ILEP coordinator. In the case that another ILEP member would like to join, or in the case that the ILEP member asks another ILEP member to join because there are gaps in funding and/or technical expertise, then we come back to the first type.

  In the case this ILEP member would like to stop its activities in this country, they can ask whether another ILEP member would like to take over his responsibility, except if local authorities can fully take over.

- Leprosy is detected in a country but not a single leprosy member is active
  
  In this specific case any ILEP member doesn’t have a mandate to interact. Yet the country can submit a request to the ILEP Office that will report at the next Members’ Assembly.

Any change in the national ILEP coordination must be reported to the ILEP Office, if possible prior to the change taking place.

**Quick wins**

At the Members’ Assembly in Würzburg in October 2017 several topics were tackled through group discussions and reports were made. Concrete actions (quick wins and long term goals) were particularly appreciated. It would be useful to have such group discussion about ILEP coordination at the Members’ Assembly of October 2018.

Alex Jaucot
Damien Foundation
8 March 2018
GUIDING PRINCIPLES FOR
ILEP COUNTRY COORDINATION
*Approved by ILEP Members Assembly on 10.03.2017*

BACKGROUND
ILEP, as a Federation of organisations all with a common vision of a leprosy free world, requires strong coordination and collaboration to reach this vision. This requires ILEP members to coordinate at the national level where the critical work is done, as well as with the international ILEP office, which is able to provide some support across country efforts.

The ILEP office facilitates the ILEP international strategy, but implementation of the strategy is conducted at the country level by the active work of ILEP member organisations. Therefore, there is a need for effective ILEP coordination and the national level amongst the members, to promote a stronger voice with external partners and provide a link and communication channel with the international ILEP office.

This Guiding Principles document provides an outline of how this can work effectively.

PURPOSE
The purpose of ILEP coordination is to increase the commitment and integration of ILEP members to achieving a world free from leprosy. By collaborating, sharing information and resources and having a stronger common voice and strategy, the overall efforts of ILEP members will be enhanced.

PARTNERS
The core partners are ILEP member organisations in the country. However the Coordinator’s role will include linking with other leprosy-related organisations working in the country, and organisations of people affected by leprosy. Beyond these coordination may include links with government departments, Inter-Governmental Organisations - IGOs (WHO, etc), universities and research centres, other NTD organisations, other disabled persons’ organisations (DPOs) as well as bodies such as alliances (international and national) and disease forums.
THE ROLE OF NATIONAL MEMBER ORGANISATIONS
ILEP member organisations should,

- Meet regularly at commonly agreed intervals
- Develop a common country strategy related to the ILEP strategy
- Communicate with other members of ILEP in country and respond to requests from the ILEP Coordinator
- Contribute to ILEP Annual Country Reports
- Dedicate financial and human resources for national meetings and other opportunities to implement the ILEP’s country strategy
- Contribute to agreed joint interventions (with or without local government) (eg implementation funding, monitoring and evaluation)

ROLE OF ILEP COUNTRY COORDINATOR
The ILEP Country Coordinator is a facilitator, representing the interests of all the participating ILEP member organisations. A key aspect of the role is co-ordinating ILEP members in activities at the country level. The following guidelines inform some of the expected roles of the ILEP Country Coordinator. They will need to be adapted for each context.

Coordination at Country Level
- Call and chair ILEP country-level meetings
- Ensure that an ILEP Country Strategy is developed, and support implementation
- Foster engagement between members, partners and government,
- Encourage local ILEP members to support joint action plans (funding, management, etc.)
- Facilitate annual ILEP reports
- Contribute to and participate in the national leprosy policy and decision making.
- Engage civil society organisations including organisations of people affected by leprosy and disabled people’s organisations.

Representation and Advocacy
- Act as the official spokesperson of ILEP in the country (and ensure that official statements and documents are recorded)
- Represent the interests of ILEP members to government and other partners
- Represent ILEP at national events, focusing on the involvement and work done by all members
- Be a national voice on issues of relevance to the leprosy community.
- Act as focus point for advocacy and action on issues of national importance that extend beyond one member or organisation of people affected by leprosy.
Engagement with ILEP International Office

- Raise issues of national level concern to ILEP international office (for broader attention across the Federation);
- Promote the ILEP strategy & vision
- Act as a liaison between the ILEP international office, local members and other local partners
- Act as focal point for ILEP-related correspondence (ensuring email communication is timely)
- Respond to and disseminate communications from Ministry of Health, Ministry of Social Welfare and other national stakeholders as well as ILEP international office
- Provide feedback to ILEP members

Term

- The ILEP Country Coordinator is appointed for a set term, however the length of term and the process for rotation will be decided locally by the members in each country.
- If there is a change of Coordinator, there will be a handover during an official ILEP national meeting, and ILEP international and key government and national leprosy programme staff will be notified.

THE ROLE OF ILEP INTERNATIONAL OFFICE

- Regular communication with ILEP Country Coordinators, keeping them informed of key ILEP developments
- Provide feedback on information requested from Country Coordinators
- Promote lessons learnt and best practices across countries
- Call for annual reports and compile the data
- Support development of country level strategies
- Maintain a knowledge platform for Country Coordinators on the ILEP website
- Look for opportunities for knowledge sharing among countries.
THE PRACTICE OF CO-ORDINATION BETWEEN ILEP MEMBERS

GUIDELINES ON CO-ORDINATION AND CO-OPERATION AT COUNTRY LEVEL

Adopted by the Working Group on Co-ordination and
Approved by the ILEP Working General Assembly

June 1995

Co-ordination is the core of ILEP; the reason for being a Member. It is both the great achievement of ILEP and the greatest cause of friction between Members. It is a balance between the desire of each Member to act with absolute autonomy and the desire of each Member to ensure that what funds are available are used to the best possible effect in support of people affected by leprosy.

The tensions inherent in this balancing act are managed by the system of co-ordinators: allocating responsibility for each project or country to a single Member whose right to act is respected by all other Members. That respect means giving up some freedom of action such that other Members only act through or in concert with the co-ordinator.

Today this system is under pressure. The old geographic separation of Members’ fields of activity is breaking down. Often many Members are, or want to be, operational on the same territory. Then divergence occurs between those who see respect for a single ILEP National Co-ordinator as the only solution, and those who see flexible co-operation as the way forward.

That divergence threatens the well-being of the Federation as complaints are heard on all sides:
- "There is no longer any other Member which shares our understanding of co-ordination"
- "We are blocked from working where we want"
- "A Co-ordinator should be our servant, helping but not controlling us"
- "There is no longer trust between associations like in the old days"
- "We need more than financial co-ordination; we need co-ordination on practical problems in the field"
- "Associations insist on their rights where they are the Co-ordinator but find all sorts of excuses for acting just as they want elsewhere"
- "Nobody bothers to read the Guide to Co-ordination or follow the agreed procedures"

The following Guidelines on co-ordination and co-operation between Members at country level have been adopted as a basis for improved common understanding and practice. The Guidelines relate to a number of aspects around which friction has commonly occurred:
1. **Appointment of National Co-ordinators**

   - To have a single Member-association as National Co-ordinator is the most straightforward way in which to ensure co-ordination in the field. Members should make every effort in each country to agree on a National Co-ordinator.

   - For the few countries where it is not possible to agree on a single Co-ordinator, Members will nonetheless devise alternative procedures to ensure co-operation between them as regards contact with the government, identification of new projects, and support of the National Programme.

2. **Agreeing the Practice of Co-ordination for each Country**

   Members vary in their ways of working; Local circumstances vary from country to country.

   It is essential, therefore, that for each country the Members active there openly discuss with each other how they expect and want the process of co-ordination to be applied. There is need for common understanding between the Members involved about the way they wish to work together within the framework laid down by the rules of co-ordination.

   It is particularly important for Members to have a common understanding of their policy regarding the development of anti-leprosy work in the country and the contribution that they can make to it. Where there is an ILEP National Co-ordinator, it is the responsibility of that Member to develop and promote such a policy, in consultation with other Members supporting that country. For countries without an ILEP National Co-ordinator, the Members involved will find other ways to agree a common policy.

   It would be good for understandings on the practice of co-ordination in a country to be set out on paper in the form of an accord between interested Members.

   The time of renewal of a National or State Co-ordination would be a good opportunity for the Members concerned to jointly review such accords and their understanding of how co-ordination should take place between them for the country concerned.

3. **Field Co-operation**

   In all countries where more than one association is operationally active, Members recognise that it is essential to promote co-operation between them in their field activities. As agreed in the Statement on Field Co-operation adopted at the General Assembly in Dublin:

   - Where a National Co-ordinator exists, that Member has responsibility for organising co-operation between Members on the ground. Other Members may reasonably expect the Co-ordinator to arrange regular consultations, to be a source of information and to facilitate their practical requirements if asked.

   - Where no National Co-ordinator has been appointed, the Members involved will instruct their Representatives to work closely together and to share the tasks that would otherwise have fallen to the National Co-ordinator.

   - Given their different structures, it would be helpful if Members could be clear about the level of authority given to each Representative. Differences on this can lead to misunderstanding.
When Representatives in a given country meet, a report of their meeting must be sent to the headquarters of the Members involved and to the Co-ordinating Bureau.

4. Contact with Governments

The purpose of all co-ordination is to avoid confusion. In dealing with government authorities it is especially important to avoid different messages being given by different Members. Thus:

- The National Co-ordinator, in discussion and in co-operation with other interested Members, must take the lead in contact with the government.

- The rules of ILEP co-ordination do NOT preclude contact with the government by other Members. Those other Members, however, MUST:
  * Discuss such contacts, in advance, with the National Co-ordinator
  * Keep the National Co-ordinator informed of the outcome of all such contacts
  * Notably, the point on which the co-ordination rules are most strict is that, in line with Bye-Law 9.4, no formal agreement shall be negotiated or signed with the government without the approval of the National Co-ordinator.

- In countries without a National Co-ordinator, it is harder but even more necessary for all Members active in the country to keep each other informed of contacts they make with the government.

It has been evident in recent years that many complaints arise because Members active in countries where several of them are operational, have NOT respected these rules:

* In countries such as Brazil and Vietnam that have a National Co-ordinator, other Members all too often have NOT kept the co-ordinator properly informed of their discussions with government.

* In countries without a National Co-ordinator such as India, Nepal, Nigeria, and China, Members do NOT make enough effort to tell each other about their plans and the visits and contacts that they make.

As regards the countries cited above, the situation has improved recently as Members set up and respect a variety of mechanisms for co-operation and consultation but there is still considerable room for improvement.

5. New Initiatives

A related area which has caused friction, is the way in which when developing new initiatives, all too often Members at best respect the rules but not the spirit of co-ordination. There is a definite tendency to tell other Members (let alone the Co-ordinating Bureau!) of new projects only after an association has already planned and decided on its support.

Where it relates to a country for which another Member is National Co-ordinator, such an approach breaches the principles of co-ordination, angers the co-ordinator, and may well mean the Member concerned does not profit from relevant information from the co-ordinator about the local situation.
Where the National Co-ordinator does not keep other interested Members well-informed, it is disrespectful and reduces their willingness to support that co-ordinator and the country concerned.

Most seriously, where there is no national co-ordinator, it means too many small, dispersed initiatives without any clear policy or impact.

Thus Members commit themselves to:

* Sharing information with other interested Members regarding new initiatives as early as possible, and before a final decision on support is taken.
* Facilitating such sharing by the development of appropriate procedures such as the newsletter on new initiatives started in India last year.

6. Knowledge of Co-ordination

Understanding of both the purposes of ILEP co-ordination and of the rules agreed over the years, is often weak among those who have to ensure its practice. It is important that not just the heads of associations but also their headquarters staff and field representatives have a working knowledge of the procedures they should be following in order that co-ordination between Members be both effective and amicable.

- Training

Training in ILEP co-ordination procedures should be made available for the staff and representatives of Members.

* Members can provide in-service training themselves.
* Individuals can be sent to the Co-ordinating Bureau for a personalised introduction to ILEP procedures.
* The Co-ordinating Bureau arranges occasional seminars. These can be arranged either in London or on a regional basis.
* When member-associations bring their Representatives together, Co-ordinating Bureau staff can lead sessions on the co-ordination procedures.

- The Guide to Co-ordination

The second edition of the Guide is about to be published. This includes all changes to the co-ordination procedures agreed since 1991. Most notably, as a result of experience with the first edition, it has been re-designed and re-written to make it more user-friendly. It is hoped that it will now be much easier for the staff of member-associations to use in answering the practical questions they face.

The Guide was always intended by Members as a working tool (Assembly, June 1989) to improve the operation of co-ordination among Members. Members, therefore:

* Will ensure that they distribute copies of the new edition of the Guide and explain its importance to all their staff whose work touches on co-ordination, notably their field Representatives and staff in Project Departments.