ILEP Members’ Assembly
Amsterdam, 10th March 2017

Annex: 4 – Triple Zero Discussion Paper

Expected outcome of the session:

Establish agreement on work plans

Decision regarding membership engagement with Triple Zero
1. INTRODUCTION TO THE TRIPLE ZERO CAMPAIGN

Achieving a world without leprosy is our vision, mapped out in the ILEP 2016 – 2018 Strategy. ILEP has also developed a campaign strategy to advocate for the implementation of the three pillars of the global strategy: the “Triple Zero Campaign”. This coalesces around the three global targets of the ILEP and aligns with the WHO Global Leprosy Strategy 2016-2020. It focuses on the coordinated efforts needed to achieve these ambitious goals.

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<tr>
<th>Campaign Target</th>
<th>ILEP Strategic Goal</th>
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<tbody>
<tr>
<td>“ZERO TRANSMISSION” Stopping leprosy transmission</td>
<td>Goal 1: We will work together and with other partners to stop the transmission of leprosy</td>
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<tr>
<td>“ZERO DISABILITIES” Preventing girls &amp; boys being disabled by leprosy. Ensuring those with existing impairments aren’t disabled unnecessarily.</td>
<td>Goal 2: We will work together and with other partners to prevent disabilities from leprosy</td>
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<tr>
<td>“ZERO DISCRIMINATION” Abolishing discriminatory leprosy laws and practices</td>
<td>Goal 3: We will work together and with other partners to promote inclusion of people affected by leprosy</td>
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To achieve these goals and targets, there is a need to consider the roles of ILEP members, the ITC, the Panel of People Affected, as well as the ILEP office.

Despite the challenges of real collaboration across a diverse federation, ILEP members have a relatively strong track record of working together in targeted programmes of action. Major initiatives based on collaboration include Leprosy Review, Infolep, LPEP, AIM Initiative, LRI, R2STOP and some larger multi-country research projects. In all of these, multiple ILEP members and partners were actively involved. Some key characteristics of these include:
The following proposals present ideas that ILEP Office would like to propose to the members for discussion and collective engagement. They seek to work towards substantial and timely outcomes in each of the “Triple Zeros” within the next few years. They are intended for discussion at the March Members Assembly, and hope to align with the proposed workplans of the ITC and Panel of People Affected.

- They address(ed) agreed major challenges or areas of concern in the field of leprosy
- They are/were multi-country projects or programmes
- They were often built on a good project, innovation or best practice
- They contribute(d) to joint aims and achieve mutually agreed results
- They were initiated by a number of ILEP members, with the option of others joining in.
- Most importantly, they involve(d) joint funding of some nature

1) **ZERO TRANSMISSION**  *How will the ILEP Federation best support and maintain the Global Partnership for Zero Transmission as a common platform for scaling up and prioritizing key initiatives?*

This initiative is to align key stakeholders to focus on the goal of achieving Zero Transmission. This process is currently underway, guided by a steering committee comprised of ILEP, Novartis Foundation, SMHF, a national programme manager, people affected by leprosy and the WHO. This process started with a planning meeting in February, and will be followed by an extensive stakeholder consultation with a launch planned for autumn 2017.

**To be discussed at the March Meeting:**
- What are Members expectations in this initiative? How do Members want to engage?
- What are the implications for ILEP at country level?
- What will be the role of the ILEP office?
- What will be the role of the ITC?
- What will be the role of the Panel?

2) **ZERO DISABILITIES**  *How might the ILEP Federation best respond to the major shifts underway in models of disability and rehabilitation services in developing countries? (Annex 1)*

WHO has proposed a major reconceptualization of the existing Community Based Rehabilitation (CBR) model. This is the approach used by many ILEP members in the delivery of disability services to people affected by leprosy. The Disability and Rehabilitation programme within the WHO is recommending a complete restructuring of CBR and a shift of responsibility from the WHO (and National Ministries of Health) to multiple international organisations and government Ministries.
To be discussed at the March Meeting:

- Is there interest and capacity to form a disabilities working group to guide the Federation and explore possibilities for implementing new approaches in endemic countries?
- Who will be on such a group?
- What will be the role of the ITC?
- What will be the role of the Panel?

3) ZERO DISCRIMINATION  How might the ILEP Federation build evidence, harness participatory action and identify effective strategies for reducing stigma and discrimination? (Annex 2)

The campaign target of working towards Zero Discrimination by abolishing discriminatory leprosy laws and practices is an important and worthwhile aspiration. A key challenge for the ILEP Federation is how to ensure a sound research and evidence-based approach in working towards this target and harness the collective of ILEP and other stakeholders to achieve this goal.

To be discussed at the March Meeting:

- Is there support for ILEP to form a coalition (between people affected by leprosy (including the Panel), the ITC, LRI, University partners, ILEP Members, and others) to:
  - identify and harmonise best practices,
  - Intensify research and maximise outcomes at the international advocacy level?

How might the ILEP Federation best respond to the major shifts underway in models of disability and rehabilitation services in developing countries?

The International disability and development sector is currently undergoing substantial change.

- At the level of service models. Existing models of service delivery are being questioned. The widely used Community Based Rehabilitation (CBR) model is being reconceptualised. The traditional role of the WHO (as the key proponent of CBR) is being revised. New models are needed.
- At the level of individuals. There is increasing recognition (especially in the case of people with leprosy-related disabilities), that the effects of poverty, discrimination and multiple disadvantage profoundly impact on how goals and plans should be set and how outcomes should be understood. New approaches are needed.

This proposal recommends that these changes should be formally discussed, it recommends the formation of a short-term working group to advance these issues and guide the Federation.

It also suggests a potential strategy that might be of relevance to these changes.

The CBR Service Model

The model of Community Based Rehabilitation (CBR) is transitioning to a model of Disability Inclusive Development (DID). While there is disagreement about a number of details, key stakeholders are recommending that:

- Internationally, responsibility for DID will be across multiple Intergovernmental Organisations (IGOs) - not just the WHO. The responsibility for disability-related issues will extend to the ILO, OHCHR, UNDP, UNESCO, etc. This means that disability-related activities will shift towards a more cross-cutting, inter-sectoral approach.
- In implementing countries, responsibility for DID will be expected to move from Ministries of Health to also include local Ministries of Welfare, Education, Labour, etc.
- There should be less emphasis on “rehabilitation” within CBR and disability services in the international development sector.
- Rehabilitation services under this new model are expected to become more comprehensive (e.g. incorporating ageing and chronic diseases) and become more closely integrated with health services. It is anticipated that the WHO will soon develop a ‘roadmap’ for such a comprehensive rehabilitation approach.
Existing Evidence within ILEP

- At the person/individual level, there is now clear evidence\(^1\),\(^2\),\(^3\) from over a decade of well-documented leprosy projects from an ILEP member in Nepal, that a Capabilities Approach (CA) has considerable impact on many of the disabling issues (motivational, social, economic, livelihood and environmental) which people affected by leprosy face.

- A Capabilities Approach, which starts by identifying people’s aspirations, leads to a number of broader outcomes. Encouraging skills, building capabilities and helping people work together can have dramatic outcomes for self-care, independence, social participation. The studies suggest that through this approach, people can become active change agents in their community, and increasingly outward looking.

The Capabilities Approach

The CA is not a particularly new or unfamiliar approach. It has been used in economics and development circles since the 90s, and is the underlying framework of the widely used Human Development Index. **The Capabilities Approach aims to empower people through focusing on, and developing, their capabilities so that they can better look after themselves.** It is basically a development approach that concentrates on the capabilities of people (and how to enhance those capabilities), so that they become capable of leading the life they value. The CA might be a useful framework for ILEP members. It may help us to be more consistent and comprehensive in helping people affected by leprosy at the personal level, and it may help us to broaden our reach and impact at the systems level.

Under a CA framework, we would see/describe a key part of ILEP’s work as the building of capabilities.
- Practically (at the person level) this may mean focusing on building people’s capabilities, rather than starting with their current impairment or level of functioning or social participation. Some ILEP members do this already in different ways, but may not explicitly use the terminology and tools of the CA.
- At the systems level, using capabilities terminology would help us speak a common language with a broad range of services, NGOs, IGOs and government ministries. For example, IGOs and ministries that deal with labour, welfare, education, etc. are not familiar with medical, physical, functional or rehabilitation terms and outcomes in the way that health-related IGOs and ministries are. We will need a new language and frameworks if we are to increasingly work outside of the health sector. Terminology (and goals and outcomes) that are about building people’s capabilities are able to be understood across all sorts of NGOs, IGOs and ministries that deal with areas such as labour, welfare, education, etc.

For example, in the context of leprosy and other disabling diseases, a CA response which seeks to **enhance a person’s capabilities based on their aspirations** would recognise that:
- A fundamentally important way of maximising a person’s capabilities (physical, social, etc) would be through early detection and effective treatment of disease.
- For those living with the longer term physical and social impacts of leprosy or other diseases, it will be particularly important to have a way of understanding their individual aspirations. That is, to assess the opportunities they have to build their capabilities:
  - Some may want surgery, footwear, or other health interventions to boost their capabilities
  - Many will express the aspiration to have greater opportunities in local social and community settings, so relevant local inclusion activities may be required
Some will have aspirations for more skills, training or income, so skills development, or income generation activities may be required
Sometimes these choices will be made with (and by) families and communities, and the decision making may require analysis of environmental barriers and other social forces. In that case capabilities might be best enhanced by advocacy or related activities
For many, the stigma and discrimination they experience will be what limits their capabilities, so local and national anti-discrimination actions will benefit them.

The crucial element of the Capabilities Approach is asking people to define their aspirations and the possibilities they see for their lives, and then working with them to then identify the barriers that impede them most. It is a participatory approach which requires understanding of the disease, as well as the person’s context and the inequalities they may face.

**ILEP Response to Shifts in the CBR Model**

Regardless of whether the disabilities working group advocates the Capabilities Approach, it is important that we in ILEP are better informed about the implications of this shift. It is important that we explore how we will respond to the needs of people affected by leprosy and other NTDs, and what distinctive we envisage in disability services which will best meet the needs of people affected by leprosy and other NTDs

**Outputs**

The short-term working group will develop:

- An ILEP response to the shifts in CBR and disability services for consideration by the Members Assembly
- Recommendations for the implementation of disability services which will best meet the needs of people affected by leprosy and other NTDs
- A proposal for aligning strategies

Annex: 4.2 - ILEP – Zero Discrimination focus area – Discussion Paper

How might the ILEP Federation build evidence, harness participatory action and identify effective strategies for reducing stigma and discrimination?

The 2015 UN Human Rights Commission resolution (A/HRC/29/L.10) on the elimination of discrimination against persons affected by leprosy and their family members, recognised that persons affected by leprosy and their family members still face multiple forms of prejudice and discrimination. More importantly, it called for specific attention to address all forms of discrimination against persons affected by leprosy, and their family members. Likewise, the ILEP strategy is very consistent with the World Health Organisation’s Global Leprosy Strategy 2016-2020 includes stopping discrimination as a key pillar. It calls for specific interventions against stigma and discrimination through collaboration and networks to address technical, operational and social issues. The key challenge is how to ensure that such interventions are effective and appropriate.

Discrimination against people affected by leprosy is global and local, public and personal, systemic and individual. Therefore a coordinated, multi-faceted approach is required to operate on multiple levels in order to reach the ambitious target of “Zero Discrimination”. We need new approaches which draw from, established research and real-life experience, which involve people affected by leprosy, and which are meaningfully integrated into practice in many countries.

Current Context

The ILEP Federation in coalition with people affected by leprosy is well positioned to establish a collective effort to tackle stigma and discrimination, and to have a profound impact on this international and multi-dimensional issue. Coordination through ILEP across member organisations, and the strengthening of partnerships with organisations of people affected by leprosy, will be a strong foundation for change towards Zero Discrimination.

A number of effective strategies for dealing with discrimination and stigma have recently been identified in the leprosy context and across a range of other contexts and diseases which are similarly stigmatised. It is important to draw from this evidence, but also to selectively translate and apply it to the leprosy context in an appropriate manner.
Principles

ILEP should seek to work in this area in a way that is:

- **Soundly evidence based.** It will take full advantage of:
  a) Research evidence that exists in the leprosy field, and in other contexts (Gender, Disability, HIV/AIDS, Human Rights, etc), which can be meaningfully translated to the leprosy context, and piloted in an endemic setting.
  b) Practice evidence that exists within ILEP member organisations & within organisations of people affected by leprosy, collaboratively including experiences and lessons learned

- **Clearly research-oriented.** This is an area which lack rigorous research, so an emphasis on research will ensure that there is a good foundation for future service planning.

- **Strongly participatory.** The project depends on the involvement of people affected by leprosy at all levels to maximise relevance and outcomes.

- **Practically implemented,** drawing on the resources of multiple ILEP members and partners and open opportunities to external funding to implement in key endemic countries, being carefully documented and researched throughout.

Proposed Outputs for Discussion

There is a need to respond to discrimination in three key areas, each addressing one of the fundamental barriers to achieving “Zero Discrimination”:

1. **Changing local attitudes and behaviours.** This area would include community based participatory research:
   1.1 **Personal change:** How can we enable people affected by leprosy to be more resilient in the face of discrimination? How do we increase education about their rights?
   1.2 **Community change:** How can we implement local attitude and behaviour change strategies which are based on evidence and local consultation, and which will help family and community members learn new ways of supporting people affected by leprosy?

2. **Changing country level services and systems.** This area would include organisational research:
   2.1 **Organisational change:** How can we form coalitions of people affected by leprosy, service providers, health workers and managers to improve mechanisms of service delivery within our member organisations and national programmes?
   2.2 **Gender focus:** How can we ensure that gender discrimination is prevented? How can we identify and address / minimize gender discrimination within our member organisations and national programmes?

3. **Changing national and international laws, policies and formal practices.** This area would include research for social change:
   3.1 **Country level change:** Working at the national level in partnership with key organisations of people affected by leprosy and with advocacy groups, media, legislators and international bodies to identify and repeal discriminatory laws and policies, and foster inclusive laws and policies.
   3.2 **International level change:** Working at the international level to monitor the implementation of the UN resolution and its principles and guidelines
Outputs of this multi-year participatory and research-based initiative would include:

- Research-based, participatory principles for action to harmonise best practices across the federation
- Pilot studies of changed attitudes/services/laws in endemic country settings, which result in evidence-based, appropriate and accessible guidelines for implementation globally.
- Research and academic outcomes

**Partners:**

This proposal is to establish a multi-year alliance with a common framework between ILEP member organisations, organisations of people affected by leprosy, the LRI, university partners and other key stakeholders to profoundly advance the agenda towards Zero Discrimination. The alliance will seek:

- Engagement and participation of key national and international associations of people affected by leprosy
- Active support of ILEP Member organisations and potential external funders
- Oversight from a key advisory team
- Coordination from ILEP Office
- Academic support from university partners
- Engagement with other key organisations including such as the Office of the UN High Commissioner for Human Rights, other agencies working in stigma and discrimination, and other NGOs working towards organisational change

Practical aspects of the work could be integrated into existing projects in endemic countries. Implementation and conducting projects in these countries will also require considerable in-kind contributions from ILEP member organisations. Such projects will value-add to the project work of ILEP member organisations.