Panel of People Affected by Leprosy ToR (2016 to 2020)

1. Background

ILEP’s strategic plan 2015-2018 acknowledges the need for ILEP to work closer with people affected by leprosy to guide its policies, governance and strategy. This would be in order to strengthen our advocacy work; acknowledge the demand of many disabled people and improve decision making in ILEP.

To this end ILEP wishes to work with a Panel of Women and Men Affected by Leprosy to provide recommendations for closer collaboration going forward.

2. Purpose

The Panel of People Affected provides advice to ILEP and its members on broad issues of policy, implementation of the ILEP strategy and interpretation of trends. It is incumbent on the Panel to work with the ILEP office to ensure the connection between the policy and the programme practice of the members.

   a) Improve ILEP’s advocacy for policies and practice on behalf of people affected by leprosy.
   b) Make practical recommendations to ILEP in order to improve strategies and plans.
   c) Provide guidance on ILEP communication and campaign material.

The Panel of People Affected by Leprosy should also find ways to collaborate and coordinate their guidance with ILEP’s Technical Commission (ITC).

3. Time frame

The panel members would serve a term of four years. After this term they can be reelected only once. If some of the current panel members stay on the panel, they would have to be re-confirmed in 2 years. Panel members may be removed from continued participation if they are unable or unwilling to comply with the requirements of membership.

The Panel should carry out a mid-term review of its functioning.

4. Principles

The principles on which the panel will work are:

   a) Adherence to all relevant human rights instruments.
   b) Understanding of the purpose of ILEP.
   c) Transparency - The panel will submit a written document accounting for their contribution in ILEP’s annual report.
   d) Accountability - The panel members will work collaboratively with ILEP leadership to seek feedback from a wide range of people affected by leprosy.
5. Operation

a) The panel will communicate electronically a minimum of once per quarter throughout the year, and at a site to be determined by ILEP at least annually for a face-to-face meeting.
b) ILEP undertakes to provide facilitation, information and support to the panel i.e. an induction programme, briefings, development opportunities as well as a per diem and expenses to attend meetings.
c) The Panel will propose its Chair.

6. Expectations of the Panel Members

- Commitment to produce and deliver the Panel’s work plan.
- To attend the Panel’s meetings, at least one will be face to face.
- Participate in at least two ILEP Working Groups Meetings / year. This could be as a participant, presenting on a key area of work or leading a discussion related to their technical area
- Be available to the ILEP office and members to answer key specific questions
- Provide feedback on policy / communication material if required.

7. Membership

a) There will be 5-7 members to the panel, all of whom will have been affected by leprosy. For the purpose of continuity, some or all of the first panel members will continue serving on the first, four year term.
b) Members will be over 18 and reflect the diversity of people affected by leprosy – by age, gender, experience and geography.
c) Members will serve for four years.
d) Members will be chosen for their:
   i. understanding of the experience of being affected by leprosy,
   ii. experience of representing and being accountable to others
   iii. skills as team workers,
   iv. strategic thinking,
   v. ability to commit the time to regularly meet and be informed by beneficiary groups,
   vi. ability to communicate well (either through an interpreter or in English which is ILEP’s working language),
   vii. experience of NGO governance is desirable