ILEP Members’ Assembly
Greenville, 20th March 2019

Annex 5 – ILEP Policy on participation by persons affected by leprosy
(proposed by Panel)

Expected outcome of session:
Adoption of Panel’s proposed ILEP policy on participation
Participation Policy for People Affected by Leprosy

Whereas persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives, as stated in the Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members.

How can we have a greater involvement of people affected by leprosy?\(^1\)

**Policy-making process:** People affected by leprosy participate in the development and monitoring of leprosy-related policies at all levels.

**Programme development and implementation:** People affected by leprosy provide knowledge and skills towards universal access through participation in the governance of global organizations and in the choice, design, implementation, monitoring and evaluation of prevention, treatment, care and support programmes and research.

**Leadership and support, group networking and sharing:** People affected by leprosy take leadership of self-care or support groups or networks, seek external resources, encourage participation of new members or simply participate by sharing their experiences with others.

**Advocacy:** People affected by leprosy advocate law reform, inclusion in the research agenda and access to services, including treatment, care and support; and for resource mobilization for networks of people affected by leprosy and for the broader response.

**Public speaking:** People affected by leprosy are spokespersons in campaigns or speakers at public events and in other arenas.

**Personal:** People affected by leprosy are actively involved in their own health and welfare. They take an active role in decisions about treatment, prevention of disability and rehabilitation.

**Treatment roll-out and preparedness:** People affected by leprosy support treatment roll-out through educating others on the importance of early detection and treatment and are involved as home-based and community health-care workers.

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\(^1\) Adapted from UNAIDS POLICY BRIEF: The Greater Involvement of People Living with HIV (GIPA)
Policy Position

To enable the active engagement of people affected by leprosy, ILEP encourages its members and partners to ensure that people affected by leprosy have the space and the practical support for their greater and more meaningful participation.

ILEP members must:

- Address and remove physical, institutional and attitudinal barriers so that people affected by leprosy can be active participants and decision makers in their communities, ILEP programmes and ILEP’s member organisations;

- Educate people affected by leprosy about their human rights and responsibilities, and build their capacity so that they can confidently and knowledgeably represent themselves and their communities, contributing to decisions made regarding the support and development of their communities;

- In many cases, People affected by leprosy are a neglected community because they are not organized to become an independent movement. This limits their ability to bring pressure on stakeholders and seek transformation or change. ILEP members must technically and financially support their desire to organize themselves in a collective manner.

- Include people affected by leprosy in ILEP activities and decision making, at all levels of the organization, ensuring their contributions are heard, valued and implemented;

- Involve people affected in developing funding priorities and in the choice, design, implementation, monitoring and evaluation of leprosy programmes from their inception.

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2 Adapted from the Leprosy Mission POL25: Policy on the participation of people affected by leprosy.