

## **The ILEP Policy for the use of language, photographs/imagery**

**Developed for the ILEP Office and ILEP Members: the ILEP Federation**

**The purpose of the Policy** is to provide a framework or guidelines for use:

1. In designing and implementing Public Relations, fundraising, disease awareness and related online/digital strategies and,
2. In written, print, digital or oral communications used in governance, strategy, advisory, policy, advocacy and lobbying initiatives, Minutes of meetings and contracts.

**The Guiding Principle underpinning the Policy** is that all written materials, spoken words, photographs or imagery used by the ILEP Federation (and associates such as interns, affiliated agencies, contractors or volunteers) must be used with integrity to respect and promote the dignity and honour of all persons affected by leprosy (or “a person”) and their families.

The Policy is intended to prevent the accidental or inadvertent use of language, photographs or imagery that would offend, affront or in any way cause a person to be hurt, lessened, disrespected, excluded or victimised by others or themselves.

It is intended that all ILEP Federation staff and their associates would be provided with a copy of the Policy to refer to. It is intended that all new members of staff of the ILEP Federation and associates would be provided with a copy of the Policy. It is intended that the Policy would be referred to on Members’ websites.

### **Language**

The Policy directs that we:

- Use language that promotes dignity and respect and recognises a person as an individual separate from the disease and focuses on their qualities rather than disabilities, unless permission is given by the person to describe the consequences of leprosy and their disability.
- Use a phrase like “person affected by leprosy” or “a person with experience of leprosy” if it is relevant to indicate that a person has been cured of leprosy.
- Do not use abbreviations like “PAL” or “LAP” because they become *just another label*.
- Do not use derogatory words such as “leper,” or words that define a person by their disease like “Hansenite.”
- Do not use the term “leprosy burden.” Burden is a negative term and it suggests that people affected by leprosy are a burden on society.

- Do not use language that promotes pity or guilt but promotes compassion and positive action instead.
- Do not refer to a person affected by leprosy as “a case” but as “a new patient.”
- Do not use the word “suspect” in relation to a person who is related or connected to a person affected by leprosy. Consider words like “close contacts” “family” “neighbours” or “friends” “who may have caught leprosy” or “who may be at risk from leprosy” instead.
- Use the word “patient” only in a hospital setting, not as a word to describe a person once they are cured of leprosy. Please do not refer in general to a person as a “former patient” or “ex-patient” once they are cured.
- Refer to a person affected by leprosy by their name when possible, with permissible and without risking stigma.

### **Case studies**

When planning to feature a person affected by leprosy in a case study, the Policy directs that we:

- Ensure that the person wishes to take part and understands why they are being asked. Ask the person if they are happy to be named or identified using their full name or location.
- Record all permissions and consents granted in relation to the use of names, photographs, location, story and so on.
- Allow the person to have the opportunity to communicate their situation themselves, in their own words.

### **Photography and imagery**

When taking a person’s photograph or making a video, the Policy directs that we:

- Ask the person for their permission to be photographed and explain in advance how their photograph may be used and the related audiences. For group photographs, each person must give their permission. If the person is a minor\*, their parents’ or guardian’s permission must be sought.
- Be aware of the potential for a bystander to become the target of stigma if incidentally included in a photograph.
- Use photos and images that portray the reality of the lives of people affected by leprosy, with sensitivity and respect for their dignity. Use photos in their true context. If a person has a disability, ask the person how they might wish their disability to be portrayed.

- Confirm that it is acceptable for a person NOT to give permission to be photographed, that there is no implied obligation in the request and that declining a request to be photographed will not result in negative consequences.

### **Documenting permissions**

When a person has agreed to be photographed, take part in a video or case study and/or has a specific request about how those photographs or videos or the case study might be used, record all details for immediate and future use. When it is not practical to obtain written permission, verbal permission should be recorded instead. Mention in the record, that this Policy has been followed.

### **Two further points for consideration:**

- If an online search is undertaken based on one person or photo and the person or photo is named or described differently in different publications or web links, it may throw up doubt around the validity of the case study and compromise its credibility. Consistency in naming is important.
- If an online search is made in respect of a person by prospective employers or other enquirers, the person may be found and linked with leprosy which in turn may result in prejudice, discrimination or damage to work or marriage prospects. It is important to consider the changing the names of young people and children used in photographs and case studies.

It is intended that this Policy will be an evolving document and it will be revised and reissued occasionally.

This version of the Policy is dated: 18 October 2016.

\*the age of a minor depends upon jurisdiction and application but is generally considered to be the age of 18.