

# Comparison between Disease focus and human rights approach

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**Nevis Mary, IDEA India**

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- **I remember Humbert Williams from Surinam (one of the first winners of Wellesley Bailey award) saying "In the past we depended on charity. Now our lives are based on human rights."**

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- **If approach to leprosy is based on charity in response to a disease, the people affected by the disease are merely receivers. When the approach to leprosy is based on human rights, the people affected by the disease are the most active participants. This is a huge difference.**

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- **At the same time, when leprosy is looked at just as a disease, there has always been a tendency to study the individuals – why did they get the disease when others didn't, are they compliant etc. This has often had tendency to blame them in some ways. In some cultures this blame results in people feeling that they are being punished in some way.**

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- **But when leprosy is looked at as a human rights issue, it is the society that is to blame. This marks a huge shift from the traditional blame on the individual to placing the blame on the society for not learning to be inclusive of everyone.**

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- **Role of persons affected by leprosy and their organisations such as IDEA in transition from disease focus to human rights approach**

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**□ However it is much more difficult to focus on the social and human rights issues and while focusing on these, it is essential that the person who has had the disease is included. It is they who have a lot to contribute to the knowledge about their own condition.**

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**□ They are not just someone affected by leprosy rather they are also experts who have a great deal of knowledge as they have experienced the nuts and bolts of their disease. Medically they may be fine from the infection point of view, but on human rights point, they have to fight against the prejudices, which are worse than facing the disease itself.**

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- **People can handle the disease and its clinical consequences face to face, but it is the societal response that damages the heart and soul of those affected. From neglect to humiliation and deprivation, it drags them into depression. And that is the juncture when many have considered suicide as the best option.**

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- **But in India, many persons affected by leprosy still live separately in colonies, segregating themselves from the society due to stigma and discrimination.**

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- ❑ **Many of them still take to begging for their livelihood as they are rejected**
  - ❑ **Some are not fit for an economic venture**
  - ❑ **They have problems in medical treatment for general health care and ulcer care**
  - ❑ **They are generally not accepted by the general hospitals**

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- ❑ **Affected persons who live in community also face similar problems and sometimes even worse than those encountered by others.**

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- **Leprosy affected persons have a major role to play in the area of advocacy, awareness generation and rehabilitation**
  - **Their involvement will be needed to promote positive perception and attitudes about leprosy, to change discriminatory legal measures, to ensure that leprosy control continues to remain an issue of public health policy.**

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- **Among leprosy affected persons, those with experience and capability can teach others about self care, how to prevent disabilities, take regular treatment, etc.**
  - **They can help in defining the quality of services and help programmes to set threshold for quality**

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- **Their participation in the evaluation can identify problems such issues as with service delivery, accessibility, best strategies in communities, etc.**
  - **They act as role models in promoting positive attitudes and fight against stigma and discrimination.**

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- **Organisations like IDEA by bringing together many organisations and networking can fight much better against stigma and discrimination.**
  - **IDEA allowed many of us to express our opinions for the first time.**

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- **Organisations like IDEA conduct workshops & education activities on different areas. They function not just as theory but living real model of empowerment to other leprosy affected persons. When we speak directly to our brothers and sisters who face our same problems, we are more credible and effective.**

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- **Together as a group we are empowered, we take positions at local, national and international level to fight for our human rights.**
  - **To work in partnership with organisations like ILEP and WHO also empowers us. We need to become stronger, involve more persons with leprosy, spread empowerment and dignity.**

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**Thank You From all the members of  
IDEA India and IDEA China, IDEA  
Nepal & IDEA International**