

Addressing the quality of life of people with severe neglected tropical disease-related disability in India

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American Leprosy Missions

Neglected Tropical Diseases (NTDs)

Buruli ulcer

Chagas disease

Dengue and chikungunya

Dracunculiasis

Echinococcosis

Foodborne trematodiasis

Human African trypanosomiasis

Leishmaniasis

Leprosy

Lymphatic filariasis

Mycetoma, chromoblastomycosis and other deep mycoses

Onchocerciasis

Rabies

Scabies and other ectoparasitoses

Schistosomiasis

Soil-transmitted helminthiasis

Snakebite envenoming

Taeniasis/cysticercosis

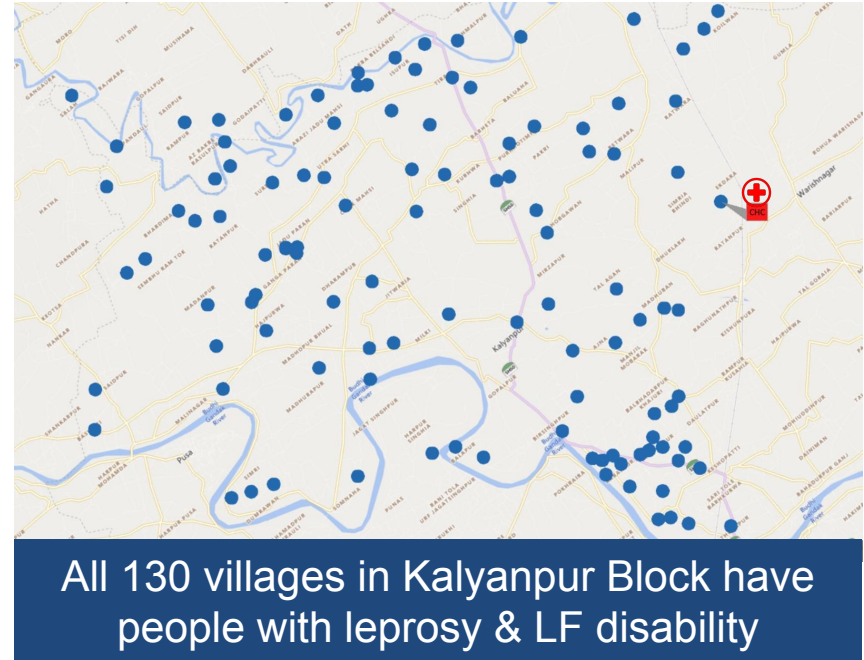
Trachoma

Yaws and other endemic treponematoses

- 20 medically diverse, bacterial, viral, parasitic, fungal, and noncommunicable diseases / diseases groups
- Impoverished environments
- Tend to coexist
- Significant morbidity / mortality
- > 1.7 billion people globally

Integrated WASH & NTDs

- 130 villages, Kalyanpur Block
- 1 Community Health Centre
- 380,000 population
- 4,729 people with chronic NTDs



Quality of Life (QoL)

- multidimensional
- individual perception
- cultural context
- aspirations, expectations, values, concerns

(adapted from WHO)



Why measure QoL of people with NTD disability?

- to measure impact
- to identify issues needing immediate attention
- to develop point-of-need interventions



QoL Tool – custom disability & context specific

- Activities of daily living
- Stigma
- Participation restrictions
- Mental well-being
- Current satisfaction with life
- Prevalent community stigma

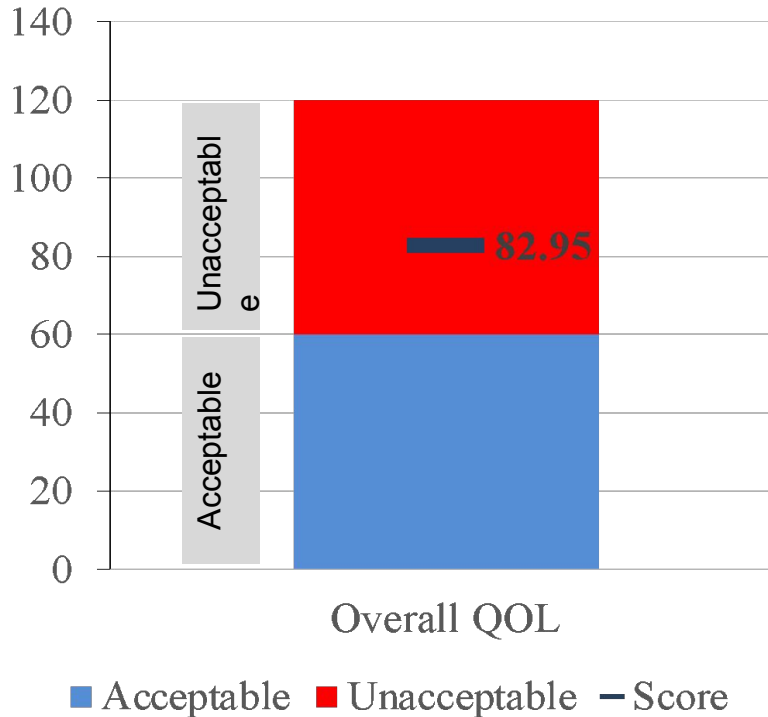


QoL Survey

- February 2022
- **150** people with severe leprosy & LF disability
- **226** community members
- **39** villages



QoL Score



- **Unacceptable** (scores ≥ 60 -120): people experience the problems '*all of the time*' / '*some of the time*'
- **Acceptable** (scores < 60): people experience the problems '*rarely*' / '*never*'
- **Overall QoL score : 82.95; Unacceptable**

Issues of people with NTD disability (n=150)

- *“I need medicines...my urgent requirement is footwear so I can walk ...”* Ram Thakur

89% (134)	mobility
88.6% (133)	finances
84.6% (127)	treatment/care
80% (120)	assistive devices
65% (98)	selfcare
54.6% (82)	personal hygiene
32% (48)	stigma
26.6% (40)	abuse
22.6% (34)	marital problems

Post -study

- Mar 2022
- 5 focus group discussions
- 59 men and women with NTD disability
- 26 villages
- Participatory design of interventions



Pilots: FY 23

HSS of Kalyanpur CHC

access to
care

Integrated footcare

mobility,
assistive
devices

People-led advocacy

self-care,
human rights

Livelihood support

steady
income, cash
flow

Lessons learned

- The world is local to the people who live within their own cultures and environments.
- Global tools miss the issues that localization makes relevant.
- Data without interventions - an academic exercise.
- When we exemplify equal partnership, we stand together as one global community to overcome the problems.

Measure what matters to people, not what matters to us.

