

## Zero Leprosy Best Practices

**Best Practice:** *Rights-based Peer Counselling to Reduce the Consequences of Stigma among Persons Affected*

### Subthemes

- Reduction of stigma, discrimination, and exclusion

### Target Audience(s)

- Policy leaders
- Health staff
- Persons affected by leprosy
- Donors

### Contributors

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### Key Messages

Peer counselling is a commonly used intervention to address the effects of health-related stigma and discrimination on persons affected and their families. The principle is that peers have personal experience of the negative effects and of ways to overcome these. With additional training, they are therefore best placed to help others in similar situations.

### Key Informant / Date Submitted

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## Description of the Best Practice

### Introduction

In many areas in Indonesia there is a high level of stigma against leprosy in the community and among religious leaders and health workers. Leprosy-related stigma can result in a range of negative impacts on persons affected, including poor mental health and quality of life, restrictions in social participation, and associated loss of employment, education, relationships, etc. (1–4).

Awareness of human rights is an important tool in empowerment.

### Objectives and Methodology

The primary aim of the rights-based peer counselling intervention was to improve the quality of life and social participation and to reduce the perception and experience of different kinds of stigma among persons affected by leprosy.

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The objectives of the project were

- To reduce the impact on stigma for persons affected by leprosy regarding their quality of life, their social participation, their anticipated, experienced, and internalised stigma, and their disclosure concerns
- To create awareness of human rights among peer-counsellors and counsees
- To improve knowledge of leprosy
- To empower people affected by leprosy who participated in the peer-counselling intervention

### Implementation of Practice

A Rights-Based Counselling Module (RBCM) was developed as training material. This module can be used with lay and peer counsellors. The Stigma Assessment and Reduction of Impact (SARI) Project selected 28 people as potential lay and peer counsellors. These individuals attended 56 hours of RBCM training, and 23 became counsellors. The counselling comprised five sessions: two were individual sessions; one was family counselling; and two were group counselling.

The SARI Project was carried out in Cirebon District, Indonesia, between 2011 and 2015. Details of the RBCM can be found in the papers by Lusli et al (5,6). The main individuals involved were persons affected by leprosy, government health workers, and members of a local disabled people's organization (DPO). A PhD student and research assistants conducted training and guided the process.

The rights-based peer-counselling intervention used low-cost methods and materials, including volunteer peer counsellors. Costs are involved in training of the peer counsellors and in ongoing monitoring of the interventions. Support for the peer counsellors is also needed.

### Results—Outputs and Outcomes

The SARI Project successfully tested the use of the RBCM with 207 counselling clients. Results documented that peer counsellors trained using the RBCM were able to achieve a significant reduction between the before and after total scores of the SARI Stigma Scale (measuring anticipated, experienced, and internalised stigma and disclosure concerns), Participation Scale Short, and WHO Quality of Life scale among the counselling clients. Qualitative data indicated that knowledge and awareness of human rights trigger change. Clients took steps to improve their life such as re-connecting with neighbours, helping in household activities, and applying for jobs. Challenges include the wish of trainee counsellors to conceal their condition and selecting persons with affinity for this type of work.

### Lessons Learned

Key lessons learned included the following

- The initial contact between the counsellor and the client is important, as at this point clients determine whether counselling could be of benefit and hence if they want to start counselling or not
- Sharing knowledge about the disease of leprosy (i.e., going beyond the simple dissemination of information) was one of the main tasks of the lay and peer counsellors
- The most important skills necessary for counsellors include listening actively, showing empathy, asking effective questions, and motivating clients to have confidence in themselves

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- Peer counsellors feel a high responsibility towards their peers. This responsibility along with their lived experience and the high trust among clients and peer counsellor can increase the potential for success of peer counsellors compared to lay counsellors
- Training and supervision are very important
- There is a need for long-term commitment and good selection, ongoing support and supervision, and trainings to review and refresh knowledge and skills of lay and peer-counsellors
- The use of the RBCM cannot yet be claimed to be a “best practice.” However, it has been tested and found to be effective in reducing the negative effects of stigma and improving the quality of life and social participation among those who were counselled.

### Replicability and Scalability

The rights-based peer-counselling intervention has been replicated elsewhere in Indonesia. It is potentially scalable since it used low-cost methods and materials, including volunteer peer counsellors. Costs are involved in training of the peer counsellors and in ongoing monitoring of the interventions. Support for the peer-counsellors is also needed. If implemented on a large scale, substantial resources will be required. However, trained peer counsellors should be able to help people other than those affected by leprosy and thus serve as part of a basic community-based mental health service.

### Conclusions

The SARI Project showed that the rights-based counselling intervention was effective in reducing stigma, promoting the rights of people with leprosy, and facilitating their social participation. The intervention should preferably be structurally embedded in the health or social services.

### References / Further Readings

1. van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, et al. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Glob Health Action* 2012;5:1–11.
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4. Dadun, Peters RMH, Lusli M, Miranda-Galarza B, van Brakel WH, Zweekhorst MBM, et al. Exploring the complexities of leprosy-related stigma and the potential of a socio-economic intervention in a public health context in Indonesia. *Disabil CBR Incl Dev* 2016;27(3):5.
5. Lusli M, Peters RMH, Zweekhorst MBM, van Brakel WH, Seda FS, Bunders JFG, et al. Lay and peer counsellors to reduce leprosy-related stigma—lessons learnt in Cirebon, Indonesia. *Lepr Rev* 2015;86(1):37–53.
6. Lusli M, Peters R, van Brakel W, Zweekhorst M, Iancu S, Bunders J, et al. The impact of a rights-based counselling intervention to reduce stigma in people affected by leprosy in Indonesia. *PLoS Negl Trop Dis.* 2016;10(12).