Background:
Persons who have experienced leprosy know about early signs of the disease and leprosy reactions, treatment by MDT, care for foot and hand wounds, and how to deal with other various challenges that the patients and those cured will face in daily life. Everybody agree that this knowledge and wisdom of the persons obtained through the experience are valuable resources that can contribute to leprosy control effectively. WHO published in 2012 the guideline for strengthening participation of persons affected by leprosy in leprosy services (abbreviated as SPP).

Purpose:
1. Targets of this handbook are both the field workers and the persons affected by leprosy.
2. This handbook must provide the target groups with practical advice and help them to implement SPP.

Content:
This handbook will consist of the following contents:

a) Why should we promote SPP, i.e. why do we need the persons affected by leprosy to participate in leprosy services?

b) What are the benefits of SPP for the field workers as well as for the persons affected leprosy?

c) How do we promote SPP and make it happen, i.e. how do we identify the persons affected by leprosy to participate and how do field workers embrace the persons in SPP?

d) Case study and relevant references

e) SPP matrix to access a reference case by country, type of activity, implementer (NGO, GO, own etc.)

f) Learning sites that one can visit
### List of all cases surveyed

<table>
<thead>
<tr>
<th>No</th>
<th>Country</th>
<th>Organization</th>
<th>Informat</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bangladesh</td>
<td>LEPRA Bangladesh</td>
<td>by Aprue Mong: <a href="mailto:apruem@lepra.org.bd">apruem@lepra.org.bd</a></td>
</tr>
<tr>
<td>2</td>
<td>China</td>
<td>HANDA Feng Keteng</td>
<td>Feng Keteng</td>
</tr>
<tr>
<td>3</td>
<td>Ethiopia</td>
<td>Fekersessel Cooperative</td>
<td><a href="mailto:tsdtn8455@yahoo.com">tsdtn8455@yahoo.com</a></td>
</tr>
<tr>
<td>4</td>
<td>Indonesia</td>
<td>PPRBM (CBR-DTC) Solo &amp; DSM Slawi</td>
<td>by Sunarman: <a href="mailto:maman_shg@yahoo.com">maman_shg@yahoo.com</a></td>
</tr>
<tr>
<td>5</td>
<td>Indonesia</td>
<td>PerMaTa Gowa, Yuliati (1)</td>
<td>Yuliati: <a href="mailto:yuli_gowa@yahoo.com">yuli_gowa@yahoo.com</a></td>
</tr>
<tr>
<td>6</td>
<td>Indonesia</td>
<td>GPDLI, Nuah P Tarigan</td>
<td>by Nuah Tarigan</td>
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<td>7</td>
<td>Indonesia</td>
<td>PerMaTa Makassar, Alkadri (2)</td>
<td>Alkadri</td>
</tr>
<tr>
<td>8</td>
<td>Indonesia</td>
<td>SCG of Pantura Sejahtera</td>
<td>Pantura Sejahtera</td>
</tr>
<tr>
<td>9</td>
<td>Indonesia</td>
<td>LPB Bone (Women Empowerment Group), Asia Pananrangi</td>
<td>Asia Pananrangi</td>
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<td>10</td>
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<td>YPPCK(Leprosy Forum), Andri Rishianto</td>
<td>Andri Rishianto</td>
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<td>11</td>
<td>Nepal</td>
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<td>???</td>
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<tr>
<td>12</td>
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<td>Yuliati: <a href="mailto:yuli_gowa@yahoo.com">yuli_gowa@yahoo.com</a></td>
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<tr>
<td>13</td>
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<td>14</td>
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<td>15</td>
<td>India</td>
<td>APAL, Rachana</td>
<td>Rachana</td>
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<tr>
<td>16</td>
<td>Nepal</td>
<td>SHG Mithakshwor Nikas, Dhanusha, Ram Biraji Rajak (Int. Ramesh Choudhary)</td>
<td>Ram Biraji Rajak by Ramesh Choudhary</td>
</tr>
<tr>
<td>17</td>
<td>Nepal</td>
<td>SHG Kapileshwor, Janakpur Municipality, Dhanusha, Maidudin Dafali (Int. Ramesh Choudhary)</td>
<td>Maidudin Dafali by Ramesh Choudhary</td>
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<tr>
<td>18</td>
<td>Nepal</td>
<td>SHG Dhirapur, Mahotari, Bindeshwor Mandal (Int. Ramesh Choudhary)</td>
<td>Mandal by Ramesh Choudhary</td>
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<tr>
<td>19</td>
<td>Nepal</td>
<td>SHG Gaurishanker, Sarahi, Nathuni Sah (Int. Indra Shahi)</td>
<td>Nathuni Sah by Indra Shahi</td>
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<td>20</td>
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<td>Laxmi Pokharel by Ramesh, Indira, Hugh</td>
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<tr>
<td>21</td>
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<td>Raksha Adhikari by Ramesh Choudhary</td>
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<tr>
<td>22</td>
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<td>HANDA Yuan Yuhua</td>
<td></td>
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<td>23</td>
<td>Colombia</td>
<td>FELEHANSEN DE COLOMBIA</td>
<td>Martha Ceciña Barbosa Ladino, GLRA Advisor</td>
</tr>
</tbody>
</table>
List of 8 good practice cases included in the booklet

<table>
<thead>
<tr>
<th>No</th>
<th>Country</th>
<th>Organization</th>
<th>Respondent (Interviewee)</th>
<th>Interviewer</th>
<th>Inform of previous survey by questionnaire</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Bangladesh</td>
<td>Federation of persons affected by leprosy and disability, Bogra</td>
<td></td>
<td>Shahed Hossein Senior Scientist, icddr,b</td>
<td>by Aprue Mong: <a href="mailto:apruem@lepra.org.bd">apruem@lepra.org.bd</a></td>
</tr>
<tr>
<td>2</td>
<td>China</td>
<td>HANDA</td>
<td>Feng Keteng President</td>
<td>Sally Qi Project Supervisor, HANDA</td>
<td>Feng Keteng</td>
</tr>
<tr>
<td>3</td>
<td>Colombia</td>
<td>FELEHANSEN DE COLOMBIA</td>
<td>Lucrecia Vasquez Acevedo</td>
<td>Flor Esperanza Rodriguez Occupation Therapist</td>
<td>Martha Cecilia Barbosa Ladino, GLRA Advisor</td>
</tr>
<tr>
<td>4</td>
<td>Ethiopia</td>
<td>ENAPAL (Fekereassel Cooperative) to be reported</td>
<td>Tesfaye Tadesse Haile Vice Chairperson</td>
<td>Managing Diretor, ENAPAL</td>
<td><a href="mailto:tsdtn8455@yahoo.com">tsdtn8455@yahoo.com</a></td>
</tr>
<tr>
<td>5</td>
<td>Indonesia</td>
<td>PerMaTa Gowa Zul, Yuli, Erna, Rahma, Sulma (4 persons)</td>
<td>Kerstin Base Member</td>
<td>Physiotherapist, PhD</td>
<td>Yuli : <a href="mailto:yuli_gowa@yahoo.com">yuli_gowa@yahoo.com</a></td>
</tr>
<tr>
<td>6</td>
<td>Indonesia</td>
<td>PerMaTa Makassar Alkhadri</td>
<td>Kerstin Base Member</td>
<td>Physiotherapist, PhD</td>
<td>Alkadri</td>
</tr>
<tr>
<td>7</td>
<td>India</td>
<td>Samutthan (APAL branch) Rachina Kumuri</td>
<td>B Vijayakrishnan Member</td>
<td>Country Representative, Fortilles India</td>
<td>Rachina</td>
</tr>
<tr>
<td>8</td>
<td>Nepal</td>
<td>Dhamsha SHG Federation Mainadin Dafali President</td>
<td>Ramesh Kumur Choudhary CBR Officer, NLT</td>
<td>Mainadin Dafali</td>
<td></td>
</tr>
</tbody>
</table>
1. Country background of leprosy
2. Organizational background
3. Participating leprosy services
4. How to work on leprosy services
5. Impact of participation
6. Motivations for participation
7. Collaboration
8. Promoting factors
9. Challenges
10. Supports
11. Future plan
12. Lesson Learnt
Guide for Interviewer

In-depth Interview Survey

of

Strengthening Participation of Persons affected by leprosy in leprosy services (SPP)

--- Guide for an interviewer ---

Background;
It has been 6 years since WHO developed and published the guidelines for Strengthening Participation of Persons affected by leprosy in “leprosy services” (SPP) Note 1) in February 2011. Although scope and scale varies depending on local situation, SPP is being practiced in many places, however, little information on SPP practice is shared with those who are interested in and planning SPP. ILEP Temporary Expert Group (TEG) conducted the survey of SPP in 7 countries by questionnaire in 2015 and collected 22 cases. In order to produce a handy booklet of good practice of SPP to be utilized at field level by those planning SPP as well as those already implementing it, TEG has decided to conduct in-depth survey by interview of the 8 cases identified as good practice out of the 22 to collect more detailed and deeper information that can become clear instructions for NGO and Government to effectively support implementation of activities by organizations of persons affected by leprosy.

Note 1): “Participate in leprosy services” means “provide leprosy services”.

Definition of leprosy services in this survey;

Leprosy services in this survey are the following seven services;

☐ Identification and Referral
   Identify persons who have clinical symptoms suspecting leprosy and refer them to health center for confirming diagnosis

☐ Follow up
   Treatment follow-up and tracing those who stopped MDT and getting them back on the treatment

☐ POD
   Prevention of disability and worsening of disability

☐ Counseling

☐ Social-economic development
   Socio-economic development (e.g. education, livelihood, housing, etc.) to become self-sustainable

☐ Awareness raising

☐ Advocacy

Information to be collected by interview;

(A) Introductory Information:
   • Date of interview:

   • Name of the interviewer, his/her designation and e-mail address:
Name of the organization implementing SPP and e-mail address or telephone No:

Name of the interviewee affected by leprosy representing the organization and his/her position

(B) Questions prior to main questions

- What services do your organization and you personally understand under the term “leprosy services”?
- Among the services answered above, which services do your organization and you personally think most important?

(C) Profile of the organization

1. E-mail address: ___________________________ Telephone: ___________________________

2. Year established:

3. Total number of its members: (affected by leprosy; not affected by leprosy; )

4. Type of the organization (multiple choice):
   - Self-care group for leprosy only
   - Self-care group for leprosy and other disadvantages
   - Self-help group for leprosy only
   - Self-help group for leprosy and other disadvantages
   - Forum of persons affected by leprosy
   - Disability peoples’ organization (DPO)
   - Advocacy group
   - Cooperative
   - Religious group
   - NGO for leprosy only
   - NGO for leprosy and other disadvantages
   - Others (pls specify)

5. Mission (purpose) of the organization (multiple choice):
   - Self care
   - Self help
   - Networking, advocacy, lobbying
   - Socio-economic development (education, livelihood, housing, etc.)
   - Other (pls specify)

6. Total number of affiliated organizations/branches, if applicable:

7. Leprosy Services that the organization is providing (multiple choice)
□ Identification and Referral
Identify persons who have clinical symptoms suspecting leprosy and refer them to health center for confirming diagnosis

□ Follow up
Treatment follow-up and tracing those who stopped MDT and getting them back on the treatment

□ POD
Prevention of disability and worsening of disability

□ Counseling

□ Social-economic development
e.g. education, vocational training, livelihood, housing, etc. to become self-sustainable

□ Awareness raising

□ Advocacy

□ Other (pls specify):

(D) Information on SPP Practice

Important notes:
I. This information is to be collected separately on each leprosy service that they provide/participate in (Refer to above Question 7).
II. If the answer representing the organization is different from the interviewee’s personal answer, please record them separately.
III. In order to collect deeper information, you may need to interview collaborators of the organization, e.g. GO officers, NGO partners, family members etc. as long as time permits.

8. Year of commencement of this specific service (Ref; Q7):
   Year of its termination, if applicable:

9. Number of persons affected by leprosy who are participating in this specific service (Ref; Q7):

10. With whose initiative did the organization start considering this specific service (Ref Q7)?
   □ Organization of persons affected by leprosy and its name
   □ Individual person affected by leprosy and his/her name
   □ NGO partner and its name
   □ Government (□ community/village/block □ district □ state/province □ national)
   □ DPO partner and its name
   □ Other (pls specify)

11. What made the organization decide to provide this specific service (Ref; Q7)?
   How about the interviewee?

* This may include but not limited to, leprosy situation, motivation/commitment of persons affected by leprosy to leprosy control, funding, human resource, partners and so on.
12. What supports, help and assistance made it possible for the organization to provide this specific service (Ref: Q7)?
   How about the interviewee?

13. What process did the organization have to go through to provide this specific service (Ref; Q7)?
   How about the interviewee?

*Step by step detailed description, which can help others to follow.*

14. Who is funding the activity for this specific service (Ref; Q7)?
   - Government (☐ community/village/block  ☐ district  ☐ state/province  ☐ national)
   - The organization’s own fund
   - Voluntary service
   - Other (pls specify)

15. Whom (partners) does the organization collaborate with to provide this specific service (Ref; Q7) and what roles are shared among them?
   - Government (☐ community/village/block  ☐ district  ☐ state/province  ☐ national)/WHO (pls describe shared roles)
   - Other organizations of persons affected by leprosy (☐ SCG  ☐ SHG  ☐ Forum
     ☐ other (pls specify))
     (pls describe shared roles)
   - Independently
   - Other (pls specify)

16. Locations where this specific service (Ref; Q7) is provided?
   - National level
   - Provincial / State level
   - District / City level
   - Sub-district / Municipal / Village / Community level
   - Other (pls specify)

17. What concrete activities does the organization do to provide this specific service (Ref; Q7)?
   How about the interviewee?
*Detailed information includes but not limited to where, what activities, how, how often, for whom, etc.*

18. What challenges did the organization encounter to provide this specific service, how did they deal with the challenges and as a result, what happened? (Ref; Q7)
   How about the interviewee?

19. What factors facilitated and promoted for the organization to provide this specific service (Ref; Q7)?
   How about the interviewee?

20. What impacts, both positive and negative, were observed by providing this specific service (Ref; Q7) on;
   □ The organization (pls describe the impacts in detail)
   □ The interviewee (pls describe the impacts in detail)
   □ NGO leprosy programme (pls describe in detail by interview with the NGO representative)
   □ National Programme at different level (pls describe in detail by interview with NPM or other health personnel)
   □ Any other persons (pls describe in detail by interview with family members, community people etc.)

21. What is the organization’s future plan regarding provision of this specific service (Ref; Q7)?

22. What supports and assistance are needed to sustain provision of this specific service in future? (multiple choice, related to 17, 18, 19, 20)
   □ Support from persons affected by leprosy (pls describe in detail)
   □ Support from NGO partners (pls describe in detail)
   □ Support from Government (pls describe in detail)
☐ Support from community (pls describe in detail)

☐ Support from family of persons affected by leprosy who is participating in provision of this specific service (pls describe in detail)

☐ Any other support (pls describe in detail)

23. Any other findings / observation of an interviewer

End of interview

* If the interviewer has any questions, please send message by e-mail to the following address; Hiroe Soyagimi (smhf_hs@tnfb.jp) copying to kerstinbeise@gmail.com, michaelcidea@gmail.com.
Schedule of production of a booklet of good practices

Revised

- July: Prepare for interview survey
  - Identify an interviewer through ILEP and INGO partners in 7 countries (Bangladesh, China, Colombia, Ethiopia, India, Indonesia and Nepal)
  - Produce a guide for interviewer
  - Produce concept of this booklet

- August: Conduct interview survey

- September - October: Check with interview records
  - If necessary, ask interviewers/partners to get further information and/or clarification

- October – December: Stories/texts writing

- January: Receive feedback to the stories/texts from the organizations practicing SPP

- February: Receive feedback to the stories/texts from TEG members

- March: Designing of the booklet

- April: Printing
## Budget

A: Cost for interview (in case only one day is required)

<table>
<thead>
<tr>
<th>Country</th>
<th>Interviewee</th>
<th>Honorarium / interview (one whole day)</th>
<th>Transportation fee</th>
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<tr>
<td></td>
<td>Name of the organization / group</td>
<td>Name of the person</td>
<td>Euro</td>
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<tr>
<td>1 Bangladesh</td>
<td>Federation of persons affected by leprosy and disability, Bogra Bangladesh</td>
<td>President of the Federation</td>
<td>€ 250</td>
</tr>
<tr>
<td>2 China</td>
<td>HANDA</td>
<td>Mr. Feng Keteng, President</td>
<td>€ 250</td>
</tr>
<tr>
<td>3 Colombia</td>
<td>FELEHANSEN DE COLOMBIA</td>
<td>Ms. Maria Eloisa Castro Rey</td>
<td>€ 250</td>
</tr>
<tr>
<td>4 Ethiopia</td>
<td>ENAPAL (Fekeresselase Cooperative)</td>
<td>President of the Cooperative</td>
<td>€ 0</td>
</tr>
<tr>
<td>5 Indonesia</td>
<td>PerMaTa Indonesia, Gowa</td>
<td>Ms. Yuliati</td>
<td>€ 250</td>
</tr>
<tr>
<td>6 Kelompok Usaha</td>
<td>KPD (KUK)</td>
<td>Mr. Alkadri</td>
<td>€ 250</td>
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<tr>
<td>7 India</td>
<td>Samuttham (APAL branch)</td>
<td>Ms. Rachina Kumari</td>
<td>€ 250</td>
</tr>
<tr>
<td>8 Nepal</td>
<td>Sarlali or Dhanusha SHG Federation</td>
<td>Mr. Mainudin Dafali</td>
<td>€ 250</td>
</tr>
</tbody>
</table>

Actual expenses to be informed
B: Cost for writing up of case stories
- 2 days required to write up one case story
- honorarium is Euro250 per day 250 x 2 x 8
- there are 8 case stories to be written up

C: Cost for English correction

D: Cost for designing

E: Printing: to be done in China by HANDA

Grand total (A+B+C+D+E) ¥2,244,632

** CHF5,000 was provided by ILEP Prof. Cairns Scholarship