



# Ten Steps

**A Guide for Health Promotion and Empowerment of People  
Affected by Neglected Tropical Diseases**

Original Work by Linda F. Lehman, Mary Jo Geyer and Laura Bolton | Updated by Linda F. Lehman, July 2015



american  
leprosy missions



# Contributions

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Health workers, community volunteers and affected persons in Angola, Brazil, Cameroon, China, DR Congo, Ghana, Ivory Coast, Liberia, Philippines and the U.S.A. over the last 30 years having leprosy, Buruli ulcer and other Neglected Tropical Diseases (NTDs) and health conditions

Expansion and combination of previous work of *“10 Tasks for people affected by Buruli ulcer who want to prevent disability – I can do it!”* and a Facilitator/Health Coach’s Guide *“Community Based Training for Preventing Disability – Detect, Cure and Care”* by Lehman et al., sponsored by American Leprosy Missions and MAP International (<http://www.leprosy-information.org/>) and work started by *Legs to Stand On (LTSO)*

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## Foreword

For centuries, the infectious diseases that are collectively known as neglected tropical diseases (NTDs) have caused immense suffering, disfigurement and lost human potential. A global effort to control these diseases is now underway, led by the World Health Organization and supported by a vast network of public and private partners. The primary focus of this effort has been to reduce the burden of – and in some cases even eliminate – the infectious agents that cause NTDs. Far less attention has been given to alleviating the suffering and improving the condition of those who already have these conditions.

*Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases* is a gift of compassion, a guide to compassionate action. It provides clear instruction in the essential practical skills needed to relieve suffering caused by NTDs, especially those that affect the limbs, such as leprosy and lymphatic filariasis. The guide is also highly relevant for people with other NTDs such as Buruli ulcer, as well as for managing skin wounds, the complications of diabetes and many other conditions.

The guide is written primarily for caregivers – health workers, traditional healers, community volunteers and teachers – who can serve as “Health Coaches” to empower affected persons, their families and their communities. It addresses not only physical health issues faced by those with NTDs, but also the crucially important problems of impaired participation, limitations in activity and stigmatizing attitudes that create barriers for people with NTDs. The authors provide both encouragement for self-care practices and instruction on when to seek further help.

Each of the ten steps is meant to be practiced, not merely read. For each step, the basics are presented first, with the possibility of expanding in the future to more advanced interventions for those with the appropriate training, experience or resources. Indeed, the guide is recommended for training people at community, local and even national levels. The spectrum of issues addressed in this volume is impressive, ranging from healthy eating and personal cleanliness to appropriate footwear and care of the skin and nails, wounds and scars.

Recent research shows that providing appropriate care for those with chronic NTD-related diseases actually improves community acceptance of drug-based interventions aimed at reducing transmission of the infectious agents that cause them. Caring for those with NTD-related diseases is not only the right thing to do from a humanitarian and ethical perspective; it also results in substantial societal and economic benefits that extend far beyond the affected individual.

I wish to thank the authors for their unwavering commitment to this project. *Ten Steps* reflects their collective wisdom, acquired through many years of dedicated work and innumerable conversations with colleagues and affected people around the world. I am grateful that they persevered in the face of many challenges. May this guide be a blessing to many.

**David Addiss, MD MPH**

Director, Children Without Worms  
The Task Force for Global Health  
July 7, 2015

# Introduction to the Guide and Support Materials

Millions of people live with the physical, psychological and social challenges of Neglected Tropical Diseases and, for many, disability is an everyday reality. Morbidity management and disability interventions can have a clear and often immediate positive impact on the lives of the people affected.

*Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases* will enable health workers, communities and the people affected to identify common problems early, take appropriate actions to prevent or minimize complications, know when and where to refer, and understand how to monitor results. Since basic care at the community level is strikingly similar across diseases, this guide facilitates and promotes integrated, cross-cutting approaches. By empowering individuals, health workers and communities to competently and confidently face disease and care challenges, overall health outcomes can be improved.

The participation of people affected by NTDs and their communities is central to planning and implementing the *Ten Steps*. But they cannot do this without the broader support of the health system. The health worker, community volunteer, educator, traditional healer or other can act as a “coach” to develop awareness and capacities

to take action. Thus, in this guide the training facilitator is referred to as the “Health Coach.”

The *Ten Steps* package contains three sets of materials: a training guide, a summary card with key messages and actions, and a manager’s executive summary of each step.

The steps within this guide are best understood and learned when participatory and problem-solving teaching methodologies are used within the local context. All steps can be taught together or individually, and repeated as often as needed until the care can be done adequately. Confidence will develop as skills are practiced and positive results are seen.

Since 2008, the *Ten Steps* model has helped to control disease, preserve mobility, prevent disability and create inclusive communities for people affected by NTDs, disability or other health conditions. It is our hope that the publishing of this updated *Ten Steps* guide will enable many more people and communities to benefit from its approach.

**Linda Faye Lehman, OTR/L MPH C.Ped**

Senior Advisor for Morbidity Management and Disability Prevention  
American Leprosy Missions  
July 7, 2015

## Cross-Cutting Issues by Type of NTD

	Leprosy	Buruli Ulcer	Yaws	Leishmaniasis	Lymphatic Filariasis	Podoconiosis	Trachoma	STH
<b>WASH &amp; Nutrition Accessible &amp; Available</b>	X	X	X	X	X	X	X	X
<b>Eye: Vision, Exposure, Trichiasis</b>	X	X					X	
<b>Sensory Loss</b>	X	X						
<b>Muscle Weakness</b>	X	X						
<b>Movement Limitation</b>	X	X	X	X	X	X	X	
<b>Dry Skin</b>	X	X	X	X	X	X		
<b>Wound Present</b>	X	X	X	X	X	X	X	
<b>Wound at or Near a Joint</b>	X	X	X	X				
<b>Scar</b>	X	X	X	X			X	
<b>Edema</b>	X	X			X	X		
<b>Footwear</b>	X	X			X	X		X
<b>Activity Limitation</b>	X	X	X	X	X	X	X	
<b>Participation Restriction</b>	X	X	X	X	X	X	X	

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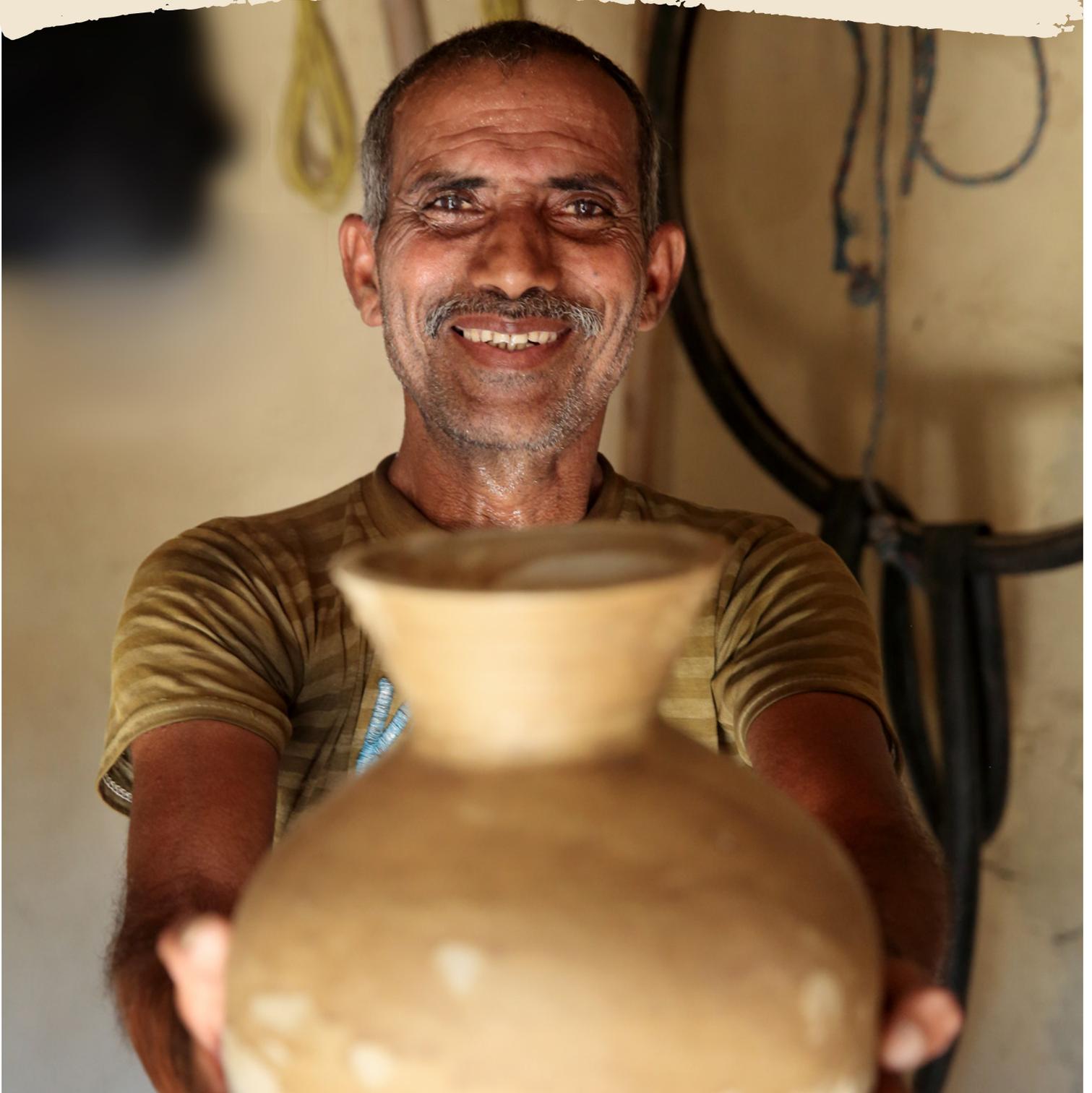
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INTRODUCTION:

# Terminology and Reflection on How to Give Help/Care

Authors: Linda F. Lehman, Mary Jo Geyer and Laura Bolton



# Introduction: Terminology and Reflection on How to Give Help/Care

## Introduction

It is important to have consistent definitions for terms such as prevention, rehabilitation and disability. This module aims to clarify terms based on the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) framework and WHO Community-Based Rehabilitation (CBR) guidelines. They both help us appreciate how diseases and health conditions can affect the whole person. The five components of CBR – health, education, livelihood, social and empowerment – are important in ensuring the inclusion of persons with disability within their communities.

This module will help participants reflect on the causes of disability, the kinds of disability and what can be done to promote health, enablement and inclusion for all. Participants will also have the opportunity to reflect on how help and care is provided and what kind of help/care best enables and empowers.

### Goals

1. Use uniform terminology when talking about disability, prevention and rehabilitation.
2. Develop confidence, enable and empower through participation.

### Key Messages

1. Prevention is the action taken to stop complications/problems from happening or getting worse.
2. Rehabilitation includes all actions aimed at reducing the impact of disability on the individual, enabling them to achieve independence, social integration, a better quality of life and self-actualization.
3. “Disability” is the term which encompasses:
  - Changes or losses in physical or mental functions and/or structure
  - Activity limitations
  - Social restrictions
  - Environmental situations which impede function
4. CBR is a community development strategy that includes key elements of health, education, livelihood, social and empowerment.
5. Explain what kind of help and/or care best enables or empowers.

### References

- <http://www.leprosy-information.org/>
- <http://www.who.int/classifications/icf/en/>
- <http://www.who.int/disabilities/publications/cbr/en/>
- [https://www.researchgate.net/profile/Johnson\\_Roch\\_Christian/publication/8668896\\_Development\\_of\\_a\\_questionnaire\\_assessing\\_Buruli\\_ulcer-induced\\_functional\\_limitation/links/0deec528ad4fee152e000000.pdf](https://www.researchgate.net/profile/Johnson_Roch_Christian/publication/8668896_Development_of_a_questionnaire_assessing_Buruli_ulcer-induced_functional_limitation/links/0deec528ad4fee152e000000.pdf)

## A Quick Supervisory Checklist

Health Coach Encourages/Teaches	Yes	No	Not Obs	Observations & Recommendations
1. Affected person and caregiver to participate in daily self-care				
2. Affected person to participate in family, school, work and community activities				
3. Affected person and caregiver to find solutions to specific participation restrictions				

### Guidelines for Teaching the Module

Facilitator/Health Coach should use the local language and ensure that all terms are found in the local language.

**Estimated time to do introduction: 4 hours**

### Learning Objectives

At the end of the module, participants will be able to:

1. Define the terms “prevention” and “rehabilitation.”
2. Define the term “disability” based on the WHO ICF.
3. Explain how a disease or health condition can affect body structures and functions, the ability to do activities and social participation.
4. Give examples of how the environment or personal factors can influence disability (positively or negatively).
5. Give examples of help and care that enable and empower.
6. Know some of the tools that are available to identify activity limitations and participation restrictions.

### List of Teaching Activities and Learning Materials

#### Activity 1

Definitions of Prevention and Rehabilitation

#### Activity 2

Understanding Disability (ICF and CBR)

#### Activity 3

Giving Help: A Story of Crossing the River

#### Activity 4

Identifying and Measuring Activity/Functional Limitation and Participation Restrictions

#### Handouts

- 0.1 WHO International Classification of Disability, Functioning and Health (ICF) Framework
- 0.2 WHO Community-Based Rehabilitation (CBR) Matrix
- 0.3 Story: Crossing the River
- 0.4 BUFLS (Buruli Ulcer Functional Limitation Score)
- 0.5 SALSA (Screening of Activity Limitation and Safety Awareness)
- 0.6 Participation Scale (Measure of Participation Restriction)

# Introduction: Terminology and Reflection on How to Give Help/Care

## Activity 1: Definitions of Prevention and Rehabilitation

### Handouts

None

### Equipment & Materials

- Flip chart stand and paper
- 4 – 6 colored markers
- 1 piece of flip chart paper per group
- 1 marker per group

### Instructions for Teaching the Activity

Room Arrangement: Divide large group into smaller groups of four participants.

- 1. Health Coach distributes large flip chart paper and markers to each group.**
- 2. Health Coach asks each group to define what is meant by the words “Prevention” and “Rehabilitation.”**
- 3. Each group discusses and writes down their definitions on the paper.**
- 4. Health Coach asks each group to read aloud their definition of the word “Prevention” with the Health Coach listing key words on the flip chart in the front of the group.**
- 5. Health Coach completes any missing key points and suggests key prevention actions that will be emphasized during the training:**
  - Taking action to stop complications/problems from happening.
  - Taking action to stop a condition from getting worse.
- 6. Health Coach asks each group to read aloud their definition of the word “Rehabilitation” with the Health Coach listing key words on the flip chart in the front of the group.**
- 7. Health Coach groups responses by “Return to normal” and “Unable to return to normal.”**
  - Return to normal function: regain movement and muscle strength; regain ability to do activities of daily living (ADL) and to participate socially.
  - If unable to return to normal functions:
    - Adapt environment and activities or use adaptations to allow activities to be done independently.
    - Ensure inclusion in family, play, school, work and community activities (social participation).

## Activity 2: Understanding Disability (ICF and CBR)

### Handouts

- 0.1 WHO ICF Framework
- 0.2 WHO CBR Matrix

### Equipment & Materials

- Projector (optional) and/or handouts
- Flip chart stand & paper
- 4 – 6 colored markers

### Instructions for Teaching the Activity

Room Arrangement: Participants sit in a circle

- 1. Health Coach distributes handouts *0.1 WHO ICF Framework* and *0.2 WHO CBR Matrix*.**
- 2. Health Coach introduces the ICF terminology and framework to discuss how health conditions affect physical/mental areas, activities and social participation. An example is given using a general health condition.**
- 3. Health Coach asks the group to apply the ICF framework to a specific Neglected Tropical Disease (NTD) such as Buruli ulcer, leprosy or lymphatic filariasis.**
- 4. Health Coach summarizes disability and its consideration of the whole person.**
- 5. Health Coach briefly introduces the *WHO CBR Matrix* with the five elements of CBR within community development to create an inclusive community.**

# Introduction: Terminology and Reflection on How to Give Help/Care

## Activity 3: Giving Help: A Story of Crossing the River

### Handouts

- 0.3 Story: Crossing the River

### Equipment & Materials

- Flip chart stand, paper and pens

### Instructions for Teaching the Activity

Room Arrangement: Participants sit in a circle

- 1. Health Coach distributes the handout 0.3 Story: *Crossing the River*.**
- 2. Health Coach reads the story of *Crossing the River* or the story is acted out by three persons.**
- 3. If acted out (dramatization):**
  - Choose three persons: one fisherman, two village persons going across the river to buy food and supplies. The Health Coach orients the three actors as to the story and its purpose and gives details about their roles.
  - The Health Coach orients the rest of the group to create a wide dangerous river on the floor with an island in the middle and “stepping stones” going to the island and also directly crossing the river.
- 4. The story of the river crossing is told or acted out.**
- 5. At the end of the story, the Health Coach asks the following questions:**
  - What was the difference in the kind of help given to each person?
  - What was the result of how each person was helped?
  - How did the fisherman feel about carrying the first person and leaving them on the island?
  - How did the fisherman feel about teaching the second person to cross the river using the stones?
  - How did each person who received help initially feel at the beginning and then how did they feel at the end of the story?
  - Is this story similar or different from how you provide help or care?
  - What kind of help or care enables and empowers?

# Activity 4: Identifying and Measuring Activity/Functional Limitation and Participation Restrictions

## Handouts

- 0.4 BUFLS (Buruli Ulcer Functional Limitation Score)
- 0.5 SALSA (Screening of Activity Limitation and Safety Awareness)
- 0.6 Participation Scale

## Equipment & Materials

- Flip chart stand, paper and pens

## Instructions for Teaching the Activity

Room Arrangement: Participants sit in a circle

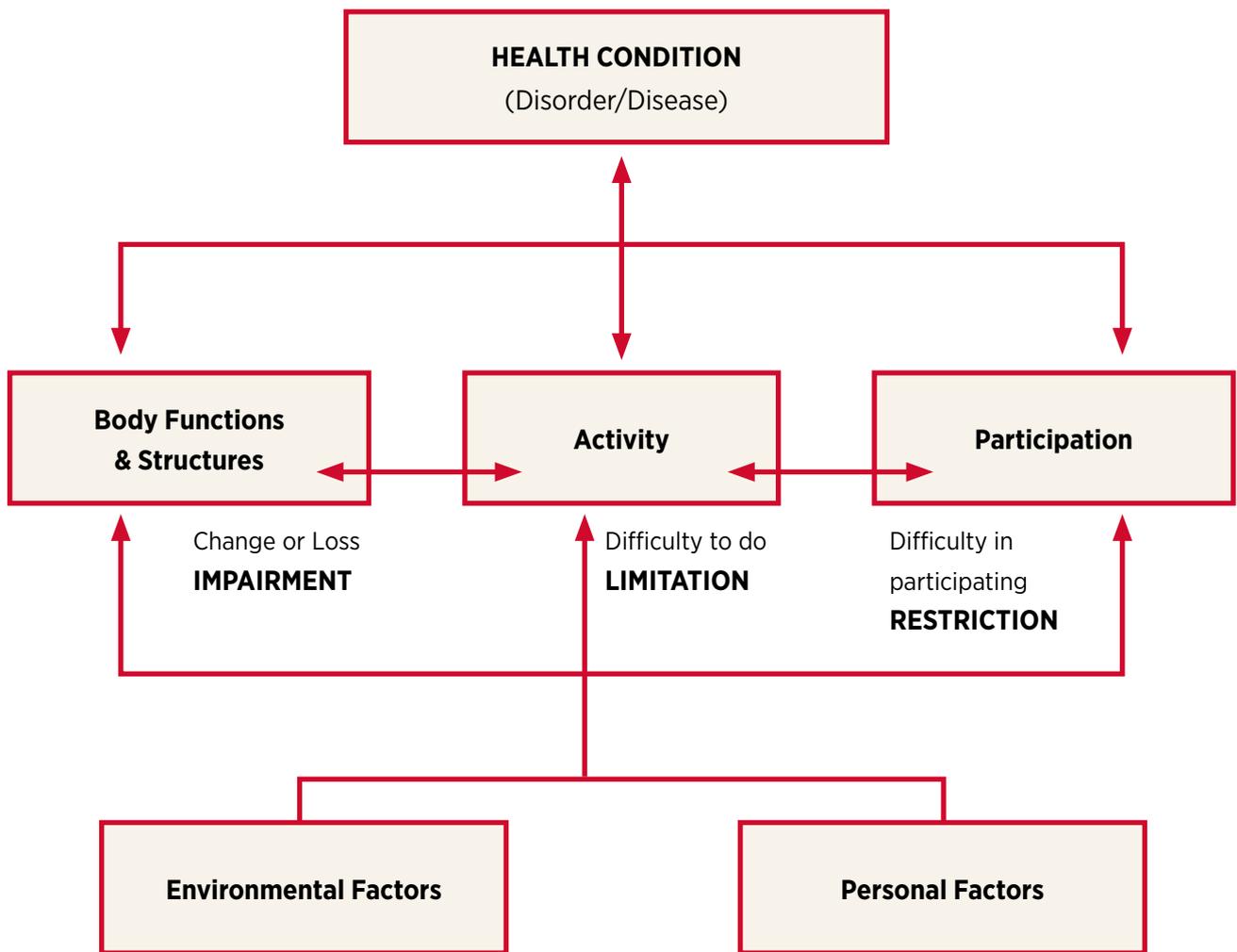
- 1. Health Coach states he/she wants to demonstrate how disease and health conditions can affect ability to do activities and participate in family, school and community life.**
- 2. Health Coach distributes the handout 0.4 BUFLS, 0.5 SALSA and 0.6 Participation Scale and reviews documents with the group and demonstrates how to use, document and score.**
- 3. Health Coach simulates situations for participants to apply BUFLS, SALSA and Participation Scale.**
- 4. One participant is selected to interview the Health Coach using BUFLS, a different participant to interview using SALSA and a last participant to interview using the Participation Scale.**
  - Situation 1 using BUFLS: Person with Buruli Ulcer having impairments on both legs that are limiting their ability to do daily activities.
  - Situation 2 using SALSA: Person with leprosy having sensory loss and clawing of fingers of both hands is having difficulty dressing and manipulating small objects.
  - Situation 3 using the Participation Scale: Person with a disease or disability that is causing them to experience participation restrictions at home, school or work and in the community.
  - All participants listen to Health Coach responses and record and score the functional limitation.
  - All participants check their work to make sure they recorded and scored accurately.
- 5. The large group is divided into three groups and the results of one of the interview situations (1, 2 or 3) is given to each group. They are asked to discuss the situation for 15 minutes and to decide what they would do to improve the situation.**
- 6. All groups present to the others what they would do to resolve the activity limitation or participation restriction. After each presentation, the larger group discusses the actions recommended.**

# Introduction: Terminology and Reflection on How to Give Help/Care

## Conclusion

In conclusion, the Health Coach summarizes the key messages and clarifies any misconceptions or questions.

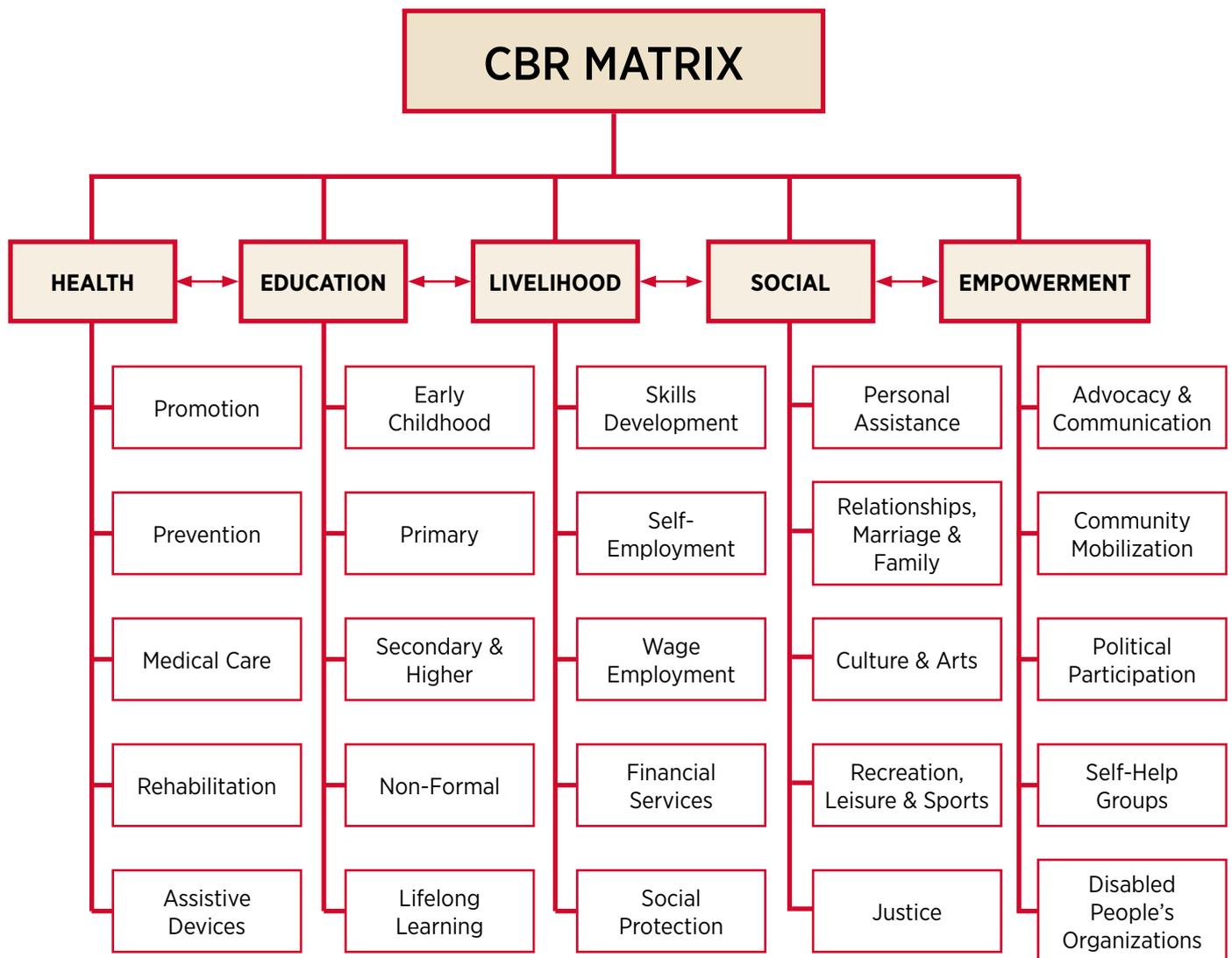
## 0.1: WHO International Classification of Functioning, Disability and Health (ICF) Framework



International Classification of Functioning, Disability and Health. WHO 2001

# Introduction: Terminology and Reflection on How to Give Help/Care

## 0.2: WHO Community-Based Rehabilitation (CBR) Matrix



## 0.3 Story: Crossing the River

### Actors

- Two villagers who live across the river on the opposite side of the market. They are both fearful of the water and do not know how to swim.
- One fisherman who knows the river well is not afraid of the river and knows how to swim.

### Story

There is a village that is divided by a wide dangerous river with an island in the middle. There are homes on both sides of the river but the market to buy food and supplies is only on one side of the river. Two neighbors need to cross over the river to buy food and supplies. There are two ways of crossing the river. The easiest is to walk across the bridge and the other is to cross the river using the stones. One set of stones goes by way of the island in the middle of the river. The other set of stones goes directly across the river without passing by the island. The river is very fast moving and has crocodiles and dangerous snakes.

Imagine you are one of the villagers who needs to cross the river but you are very afraid of the water and do not know how to swim. You decide to walk across the bridge to the market with your neighbor to buy food and supplies for your family and for a birthday party. You must be back home before the children get home from school and before it gets dark.

You buy lots of supplies and food and start back home but you discover the bridge has broken and fallen down, making it impossible to use the bridge to get home. You have been told that it may take over a week to get the bridge repaired. Both of you are

standing beside the river holding all of your purchases and crying. You are discussing how to get home and believe it is impossible. You expect your children home soon and you must finish the preparations for the birthday celebration. In addition, within a couple of hours it will be dark. Imagine how fearful you would be to use the stones if you did not know how to swim and knew that there were dangerous crocodiles and snakes in the river.

A fisherman is walking by the river and sees the both of you crying and he asks what is wrong. You tell him you cannot swim and you must get home soon. He tells you, "It is easy, I know how to walk across the river using the stones and I can carry you." Both of you start to climb up on the fisherman's back with all your purchases and he tells you that he can only carry one at a time. The fisherman picks up the first person with all their purchases on his back and starts to cross the river using the stones. He soon discovers with all the weight he cannot make it across the river but only as far as the island. He tells the first person that he is just too tired and can't go further and that he must leave them on the island while he returns to help the other person.

On the way back the fisherman thinks about the difficulty and knows that he will not be able to carry the second person. When he arrives to the side of the river, the second person starts to climb up on his back to be carried. The fisherman says, "No, I can't carry you. We must find another way for me to help you cross the river." The fisherman says, "I have an

Continues on next page

# Introduction: Terminology and Reflection on How to Give Help/Care

## 0.3 Story: Crossing the River (continued)

idea, you can cross by learning to walk on the stones.” The second person begins to cry and says he can’t swim and is afraid. The fisherman assures the second person that he will help him learn to cross the river and then holds out his hand to guide and teach the second where to step. Within a short time, the second person becomes confident in his ability to do it and tells the fisherman that he can let go of his hand. He demonstrates to the fisherman that he is able to follow him across the river to the other side. Both the fisherman and the second person jump with joy when they reach the other side. The second villager says, “I can do it!”

Both almost forget the first villager who was stuck on the island. Imagine being stuck on the island alone with nightfall coming soon. How would you feel? How would you feel if you were the second villager who learned to cross the river, stepping on the stones? How do you think the fisherman felt about leaving the first on the island and then teaching the second villager to cross alone? Now reflect on ways you help others and how others have helped you. Which way do you prefer? Why? How did participation or lack of participation affect your learning and confidence?

### Providing Help & Care – Questions for Reflection:

1. **What was the difference in the kind of help given to each villager?**
2. **What was the result of how each villager was helped?**
3. **How do you think the fisherman felt about carrying the first person and leaving them on the island?**
4. **How do you think the fisherman felt about teaching the second person to cross the river using the stones?**
5. **How did each villager feel at the beginning and then how did they feel at the end of the story?**
6. **Is this story similar or different from how you provide help or care?**
7. **What kind of help or care can enable and empower?**

## Handout 0.4: BUFLS (Buruli Ulcer Functional Limitation Score)

Adapted from 2009 Benin BUFLS Form

Date (dd/mm/yy): ____/____/____		<b>Not Applicable*</b>	<b>Can not do at all</b>	<b>Can do with difficulties</b>	<b>Can do easily, on normal level</b>
Name: _____			<b>2</b>	<b>1</b>	<b>0</b>
Age: _____ Gender (circle): Male   Female					
Education Level: _____					
Work: _____					
Interviewer: _____					
<b>Activity (Total 19)</b>					
Preparation of Food and Eating	1. Fetching water from pump				
	2. Pound fufu/manioc				
	3. Pouring water from a bottle into a glass				
	4. Cutting vegetables with a knife				
Clothing and Personal Care	5. Putting on T-shirt				
	6. Wash yourself				
	7. Cleaning yourself after going to toilet				
Working	8. Using a cutlass				
	9. Heave loads on head				
	10. Carry harvest home				
	11. Open bottle with screw top				
	12. Tie a knot				
Mobility	13. Walking on level ground				
	14. Walking uphill				
	15. Walking downhill				
	16. Running				
	17. Squatting				
	18. Kneeling				
	19. Standing up from floor				
Total number of possible activities: 19 x 2 (max score) = 38		Total x 2	Total x 1	Total x 0	
Total activities done: _____ x 2 = a. _____		b. _____	c. _____	d. 0	

Percent of Functional Limitation Calculation:  $b+c+d = \frac{\quad}{a} \times 100 = \quad\% \text{ Functional Limitation}$

Comments:

\* If more than six activities are “not applicable,” no functional limitation score can be calculated.

## Handout 0.5: SALSA (Screening of Activity Limitation and Safety Awareness)

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: \_\_\_\_\_ Occupation: \_\_\_\_\_

Clinical Record No. \_\_\_\_\_ Interviewer: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

	ACTIVITY	<b>SALSA SCALE</b> Screening of Activity Limitation and Safety Awareness  Circle the number on the line which responds to each question	If YES, how easy is it for you?			If NO, why not?	
			Easy	A little difficult	Very difficult	I don't need to do this	I physically cannot
1.	Mobility	Can you see (enough to carry out your daily activities)?	1	2	3	0	4
2.		Do you sit or squat on the ground?	1	2	3	0	4
3.		Do you walk barefoot? i.e. most of the time	1	2	3	0	4
4.		Do you walk on uneven ground?	1	2	3	0	4
5.		Do you walk long distance? i.e. longer than 30 minutes	1	2	3	0	4
6.	Self-care	Do you wash your whole body? (using soap, sponge, jug; standing or sitting ...)	1	2	3	0	4
7.		Do you cut your fingers and toenails? e.g. using scissors or clippers ...	1	2	3	0	4
8.		Do you hold a cup or basin with hot contents? e.g. drinks, food ...	1	2	3	0	4
9.	Work	Do you work with tools? i.e. tools which you hold in your hands to help you work ...	1	2	3	0	4
10.		Do you carry heavy objects or bags? e.g. shopping, food, water, wood ...	1	2	3	0	4
11.		Do you lift objects over your head? e.g. to place on a shelf, on your head, to hang clothes to dry ...	1	2	3	0	4
12.		Do you cook? i.e. prepare food both hot and cold	1	2	3	0	4
13.		Do you pour hot liquids?	1	2	3	0	4
14.		Do you open/close screw-capped bottles? e.g. oil, water ...	1	2	3	0	4
15.		Do you open jars with screw-on lids? e.g. jam, mayonnaise ...	1	2	3	0	4
16.	Hand Dexterity	Do you handle or manipulate small objects? e.g. coins, nails, small screws, grains and seeds ...	1	2	3	0	4
17.		Do you use buttons?	1	2	3	0	4
18.		Do you thread needles? i.e. pass thread through the eye of a needle	1	2	3	0	4
19.		Do you pick up pieces of paper, handle paper or put it in order?	1	2	3	0	4
20.		Do you pick up things from the floor?	1	2	3	0	4
Sub-total scores			(S1)	(S2)	(S3)	(S4)	(S5)

SALSA Score (Add up all subtotal scores S1+S2+S3+S4+S5) \_\_\_\_\_

## Handout 0.6: Participation Scale (Measure of Participation Restriction)

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: \_\_\_\_\_ Occupation: \_\_\_\_\_

Clinical Record No. \_\_\_\_\_ Interviewer: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

<b>Participation Scale</b>		Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
1.	Do you have equal opportunity as your peers to find work?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
2.	Do you work as hard as your peers do? (same hours, type of work, etc.)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
3.	Do you contribute to the household economically in a similar way to your peers?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
4.	Do you make visits outside your village/ neighborhood as much as your peers do? (except for treatment) e.g. bazaars, markets		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
5.	Do you take part in major festivals and rituals like your peers do? (e.g. weddings, funerals, religious festivals)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
6.	Do you take as much part in casual recreational/ social activities as do your peers? (e.g. sports, chat, meetings)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
7.	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
8.	Do you have the same respect in the community as your peers?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
9.	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	

Continues on next page

## Handout 0.6: Participation Scale (Measure of Participation Restriction) (continued)

Participation Scale		Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
10.	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
11.	Do you visit other people in the community as often as other people do?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
12.	Do you move around inside and outside the house and the village/neighborhood just as other people do?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
13.	In your village/neighborhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
14.	In your home, do you do household work?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
15.	In family discussions, does your opinion count?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
16.	Do you help other people? (e.g. neighbors, friends or relatives)		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
17.	Are you comfortable meeting new people?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	
18.	Do you feel confident to try to learn new things?		0								
	[If "Sometimes" or "No"] How big a problem is it to you?						1	2	3	5	

### Comments:

### Grades of participation restriction:

Without Significant Restriction	Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction
0 – 12	13 – 22	23 – 32	33 – 52	53 – 90