



AUGUST 2019

This manual is part of a project that was funded by the Leprosy Research Initiative (LRI) under project number 706.18.46.

Authors:

Pim Kuipers

Zoica Bakirtzief da Silva Pereira

Anna Tiny van 't Noordende

Strong as bamboo in a storm

Bouncing back from leprosy
discrimination

Contents

Introduction to the manual	2
Questions we ask before and after the programme	5
Resilience manual: checklist.....	7
Diagram of the project (all weeks)	9
Rules for the ‘Leprosy Game’ (week 2).....	10
Supporting stories	12
Week 1. Resilience is bouncing back from difficulties (such as discrimination)	14
Week 2. Knowledge about leprosy helps us bounce back	20
Week 3. A positive view of ourselves helps us bounce back	23
Week 4. Positive ways of thinking help us bounce back.....	28
Week 5. Accepting our (changing) body help us be tall and flexible when we face pain, limitations and shame	33
Week 6. Knowing our rights can help us be strong and bounce back	37
Week 7. Beliefs and faith help us to bounce back (from difficulties like discrimination)	42
Week 8. Strong families help us to bounce back (from difficulties like discrimination).....	46
Week 9. Strong relationships outside the family help us to bounce back (from difficulties like discrimination).....	50
Week 10. Having fun and bouncing back with other families.....	54

Introduction to the manual

Background information

Persons affected by leprosy and their family members still encounter many types of prejudice and discrimination. People affected and their family members may experience rejection, abuse, limited marriage prospects, divorce, loss of employment, loss of self-esteem, lack of respect, reduced social status and limited mobility.

The concept of “resilience” could be very helpful here. ‘Resilience’ can be understood as “being strong and bouncing back.” In that way, resilience is like the bamboo that bends and bounces back, not like the tree that breaks in a storm. Bamboo survives in difficult conditions, still standing tall and staying green all year. When there is a storm, bamboo bends with the wind. When the storm is over, it resumes its upright position. Resilience relates to skills, knowledge and confidence to take more control of your life and cope with difficulties. Resilience can help people to successfully adapt to difficult or challenging life experiences. Resilience can be learned through how we think about and react to difficult situations.

Based on our research, we think that if people affected by leprosy and their families are helped to be more resilient, they can learn to “bounce back” from acts of discrimination. They can also learn ways to be stronger to resist discrimination in future.

This manual on building resilience is part of a research project that aims to build individual and family resilience in the face of leprosy-related discrimination. This manual is based on evidence found in the English and Portuguese literature, interviews with persons affected by leprosy and discussions with health workers and people working in leprosy services.

This research project is funded by the Leprosy Research Initiative (leprosyresearch.org) and has project number 706.18.46.

This manual

The purpose of this manual is to build individual and family resilience in the face of leprosy-related discrimination. Helping individuals and families to bounce back and be even stronger. The intervention is intended to be implemented at family level. Each family should have at least one family member who is affected by leprosy.

There are ten different sessions that are separately discussed with the family. These sessions are:

1. Resilience is bouncing back after difficulties
2. Knowledge about leprosy helps us bounce back after difficulties
3. A positive view of ourselves helps us bounce back
4. Positive ways of thinking help us bounce back
5. Accepting our (changing) body helps us bounce back
6. Knowing our rights can help us be bounce back
7. Beliefs and faith help us bounce back from problems
8. Strong families help us bounce back
9. Strong relationships outside the family help us bounce back
10. Having fun and bouncing back with other families.

Approximately one week before session one, please collect the following data with each family member:

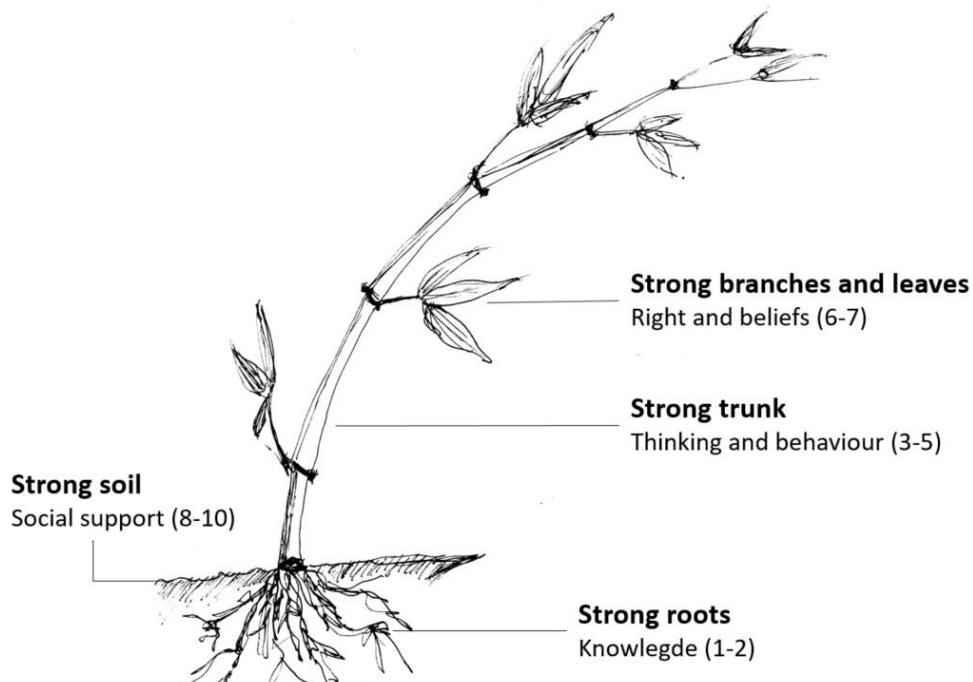
- Complete the demographic details form
- Complete the WHOQOL-BREF
- Complete the CD-RISC.

Approximately one week after session ten, the following data are collected with each family member:

- The WHOQOL-BREF (a second time)
- The CD-RISC (a second time)
- Conduct the simple interview (open ended questions), and write down the key points made

There is approximately one week between each session, the sessions should be conducted weekly.

Throughout this manual we will refer to ‘being strong and bouncing back like bamboo in a storm’, which is a metaphor we will use for being resilient. The different sessions/weeks each refer to one aspect of the bamboo about being resilient, see image below.



The first two weeks help participants learn about the idea of resilience, that is like the strong roots that bamboo needs in a storm. Weeks 3, 4 and 5 describe resilient ways of thinking and behaving (they are like the trunk or the stem of the bamboo). Weeks 6 and 7 tell participants about their rights and beliefs, they are like the branches and leaves of resilient bamboo. Finally, the social support around people (weeks 8, 9 and 10) is like the soil which the bamboo needs to be strong and cope with the storm.

The manual format is as follows. Each section starts with a week number and a title for each session/week. For the first session for example, it looks like this: “**Week 1. Resilience is bouncing back after difficulties**” (in larger font).

After that, the manual is divided in several sections:

- **What to bring**

This is a checklist for items to bring relevant for this week/session. For example, a pen, paper or a story.

- **Aims**

This is an overview of things we want the families to learn this week/session. This information is for the facilitator only, it does not have to be read to the participants.

- **Evidence**

This is an overview of why it is important to address the aims. This information is for the facilitator only, it does not have to be read to the participants.

- **Introduction**

This is a brief guideline on how the facilitator should start the week/session.

- **Activity 1**

The first activity is described step-by-step. Sometimes, examples are given in *italics*. These examples are possible answers to the questions that were asked. These examples should not be read out loud straight away, they are simply reminders for the facilitators of what could be possible answers. Other answers can also be correct. Do not read out the examples straight away, but let the family try to figure out answers first. In addition, there are ‘key messages’ at the end of the box. At the end of the activity, the facilitator must check whether all key messages have been conveyed to the family. They should be emphasized during or after the activity.

- **Activity 2**

The second activity is described step-by-step.

- **Review**

This box shows questions to ask after each session/week, to reflect on what was discussed and learned. The facilitator is welcome to add questions in order to promote further thinking about the key messages of this session/week.

- **Resources of this week**

In the ‘resources’ section, references used for the evidence sections are noted down. This information is for the facilitator only, it does not have to be read to the participants.

There are two types of boxes in the manual: one with a grey and one with a clear (or white) background.

The information in the boxes with a grey background is for the facilitator only, it does not have to be read to the participants.

The clear boxes describe activities to be conducted with the families and messages to be conveyed. The facilitator should read these instructions carefully and carry out the activities described in the boxes.

Questions we ask before and after the programme

In this project, you will be required to:

- Complete some formal questionnaires with participants (family members)
- Ask participants some open-ended interview questions (after the 10 week program).

The formal questionnaires (CD-RISC and the WHOQOL Bref) are to help us to specifically see what sort of outcomes might have come from the programme. Please follow the instructions on each questionnaire, asking each individual one at a time for their responses.

The open-ended interview questions are at the end of the program, and they are to help us understand what the participants thought about the programme, what has worked for them and how they feel about it. In this case we want to know exactly what the participants said (regardless of what you or others think about the program).

You will have to help people feel at ease and when necessary ask for details. It is important that you do not lead participants to respond in a certain way or call for only “yes” and “no” answers.

For both types of questions, it is important to emphasise that this is a research project, so we want to understand if the programme works or not. If people say negative things in the interviews, we want to know that, in the same way as we want to know any positive things they say.

Consent

Everyone who participates in the programme should have freely consented, without being unfairly pressurised. This means they should be well-informed about what the programme entails, and you should reassure them that declining will not affect any services they receive. Please make sure you complete the written consent form with each participant.

Confidentiality

You should do your best to create an environment where people are free to say what they want and confident that things they say will be kept confidential. Keep all of the interview and questionnaire responses confidential. Make sure they are not given to other family or community members, and are not left lying around in notebooks or un-protected computer files.

Implementation of the intervention

In this program we want all family members to be actively involved in the discussion and activities. It doesn't matter if people are not literate or only have little schooling, the program focuses on their life experiences, their views and how they feel about things.

It is important for facilitators (and especially those who are used to providing health education) not to “teach” these sessions. We want to encourage discussion, to listen and encourage people to draw from their own understanding. While there are some things to learn, we want to stimulate participants' thinking through problems and imagining various life situations.

The manual will provide activities to be conducted by the facilitators. These activities are followed by a series of questions that will lead participants to think through new and old ways of thinking about life. The questions are meant to encourage thinking, discussion and reflection.

Asking questions to promote interaction and debate among participants can be difficult, but it is important. The facilitator should give time for participants to think through the questions. There are

no right or wrong answers in the program.

The following questions might help if you do not fully understand a response or when you want to obtain more specific or in-depth information:

- Can you tell me more about that?
- Is there anything else?
- Why (did you do that)?
- How did others see it?
- Can you think of another example like this?
- What else can you remember about that situation?
- How did that make you feel?

Discussion should be stimulated by giving examples from your own experience, and by waiting long enough to allow participants to form their own opinion. In the beginning people feel insecure about their ideas and opinions especially in front of a knowledgeable person like the facilitator. As they start talking and feel that they are not “corrected”, they will feel more at ease to share further ideas and opinions.

Resilience building in this intervention will rely on the quality of interaction and participation in proposed activities. Therefore, facilitators should try to listen attentively and use probing “open ended” questions.

Resilience manual: checklist

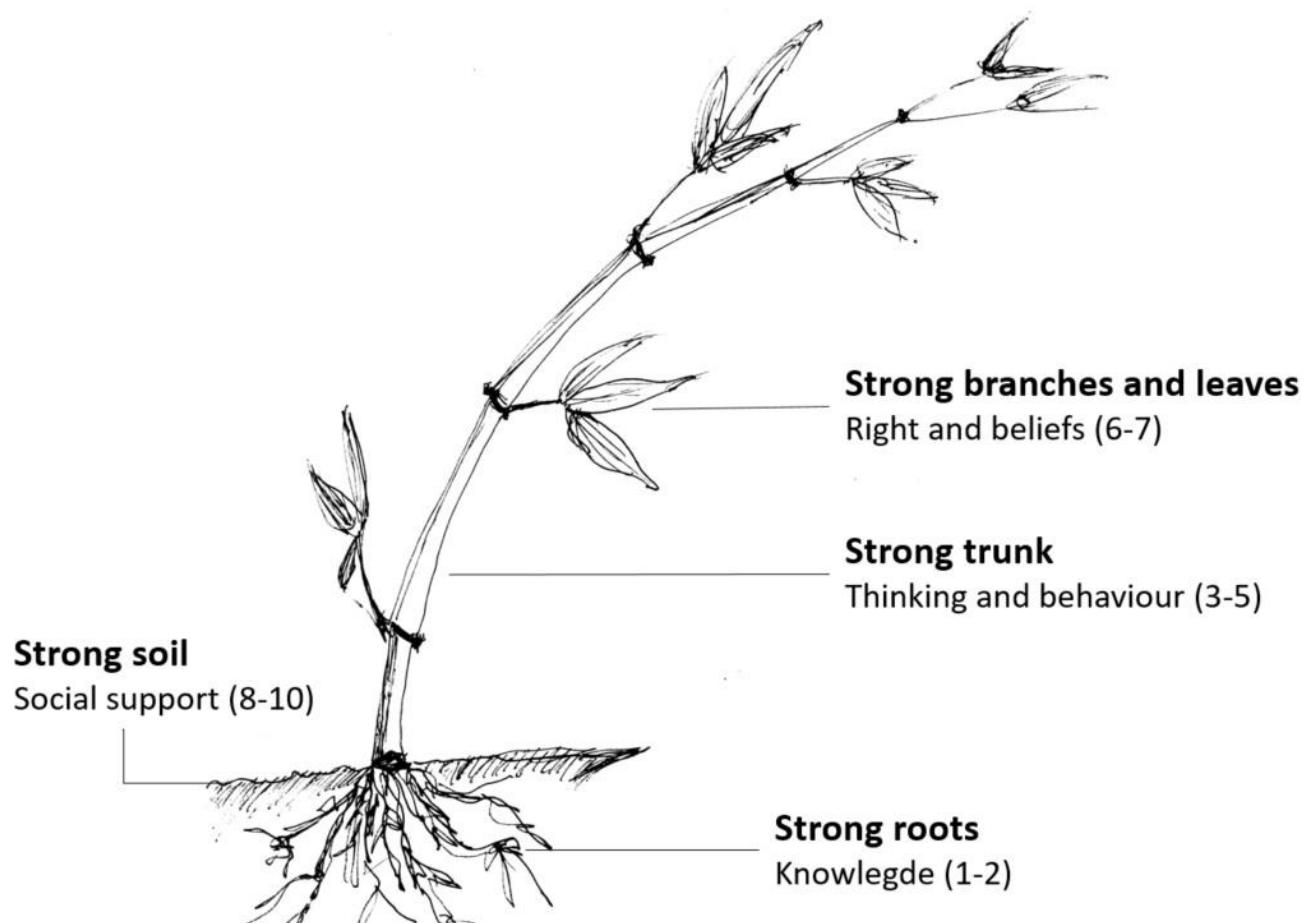
Items in red are different annexes and can be found elsewhere.

Items in blue can be found below this checklist.

Week ¹	What to bring:	What to prepare:
1	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction and review</i>) <input type="checkbox"/> Two big sheets of paper and some felt pens (<i>activity one and activity two</i>).	Be ready to explain to the family (<i>introduction</i>): <ul style="list-style-type: none"> ○ The name of that a person you know of, who has had a lot to deal with in life, and has been able to cope and ‘bounce back’. ○ What did that person have to cope with? ○ What characteristics or qualities did that person have? ○ What skills did they use to overcome their problems? ○ What sources of social support did they use?
2	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>) <input type="checkbox"/> The leprosy board game (A3 or A2 size, ideally glued to a piece of cardboard) (<i>activity one</i>) <input type="checkbox"/> The board game rules (<i>activity one</i>) <input type="checkbox"/> Differently coloured pieces, one for each family member and a dice (<i>activity one</i>) <input type="checkbox"/> ‘Flipbook’ (<i>activity two</i>)	Please note that the leprosy board game should be A3 or A2 size (printed) and ideally be glued to a piece of cardboard.
3	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>) <input type="checkbox"/> Story: Vivek (<i>activity one</i>). <input type="checkbox"/> Camera or phone to take a picture	
4	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>) <input type="checkbox"/> A cup to be filled with water (<i>introduction</i>). <input type="checkbox"/> Story: two perspectives (<i>activity one</i>) <input type="checkbox"/> Story: Vivek (<i>activity two</i>) <input type="checkbox"/> A pen and paper (<i>review</i>) <input type="checkbox"/> A pen and paper for each participant (<i>review</i>)	
5	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>) <input type="checkbox"/> Story: from impaired to proud (<i>activity two</i>)	
6	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>)	

	<input type="checkbox"/> Four envelopes: Envelope 1 includes one small stick or toothpick, Envelope 2 includes 2 small sticks or toothpicks, Envelope 3 includes 3 small sticks or toothpicks, Envelope 4 includes 4 small sticks or toothpicks (<i>activity one</i>) <input type="checkbox"/> Story: Aparna (<i>activity two</i>) <input type="checkbox"/> A folder about disability benefits / disability ID (<i>review</i>)	
7	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>) <input type="checkbox"/> Story: a father with leprosy (<i>activity one</i>)	Answers to the questions of story: a father with leprosy (<i>activity one</i>)
8	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction and review</i>) <input type="checkbox"/> Story: Bishnu (<i>activity one and two</i>)	
9	<input type="checkbox"/> A copy of the diagram of this project (<i>introduction</i>)	
10	<input type="checkbox"/> Testimonial videos of Rachna and Amal and a screen to display the videos (<i>introduction</i>) <input type="checkbox"/> Music and chairs to play musical chairs, the volume should be adequate (<i>activity one</i>) <input type="checkbox"/> A printed picture of each of the families (<i>review</i>)	<p>The following is important to arrange <u>before</u> the gathering:</p> <ul style="list-style-type: none"> ○ Prepare the facility where the gathering will take place. Ensure this facility has a screen to display videos and enough chairs for musical chairs. ○ Inform participants where the gathering will take place. ○ Make the arrangements for food and drinks. ○ Make arrangements for transportation of families to the venue.

Diagram of the project (all weeks)



Rules for the ‘Leprosy Game’ (week 2)

These rules have been taken from <https://www.mastersofgames.com/rules/goose-game-rules.htm> and have been adapted.

Equipment

The game is played on a spiral shaped board consisting of 53 spaces. There are differently coloured pieces and one six-sided dice.

Preparation and objective

Pieces are placed on the starting space, the arrow, at the outside of the spiral. Highest roll of the dice starts. The leprosy game is a simple race game – the first person to reach space 53 wins.

Play

Players take turns to roll the dice and move their piece forward the number shown on the dice.

If your first throw is six, move to space 6.

If your first throw is five, move to space 5.

- If a piece lands on the same space as someone else, both pieces have to move back four spaces.
- If a piece lands on a space with a picture, that person must follow the stated rule:

Space	Name	Rule
6	The houses	<u>Congratulations</u> . You notice early signs of leprosy on a neighbour: skin patches that have no sensation. Take them to the nearest health facility for examination. Go to space 10.
12	The treatment	<u>Congratulations</u> . You have taken your first dose of Multi-Drug Therapy (MDT) and are no longer contagious. Did you know that leprosy is no longer contagious after the first dose of MDT? Celebrate that leprosy is a disease like any other disease and go to space 14.
15	The ladder	<u>Congratulation</u> . You run into a friend who is affected by leprosy. She is not feeling well: she is ashamed of her disease. Support her and let her know that she is not alone and that you support her. Have some tea together at the restaurant that is at the top of the ladder. Climb the ladder up to space 24.
19	The gossip	<u>Sorry</u> . Your community members are angry. They think leprosy is caused by sins from a past life and that you can get leprosy from a simple touch. Miss one turn, to explain to your community members that leprosy is only caused by a bacteria and is curable.
28	The health workers	<u>Sorry</u> . You were supposed to receive a new dose of Multi-Drug Therapy (MDT) but you forgot to go to the health centre to pick it up. Leprosy medication is free of cost and available at the health centre and government hospital. Go back to space 20 to pick up your medication.
29	The rocket	<u>Congratulations</u> . You have completed your six or twelve month course of MDT treatment. Because you took your treatment on time, you have prevented disabilities. Celebrate that you've completed your treatment and are completely cured and go to space 36.
44	The blue toolbox	<u>Sorry</u> . You noticed early signs of leprosy (skin patches that have no sensation) a few years ago already, but have not gone to the health centre for examination and free treatment. As a result of taking treatment very late, you have developed disabilities. You have developed a claw hand. Go back to space 34 for reconstructive surgery of your hand.

47	The warning sign	<u>Sorry.</u> You notice that a few of your patches have become red, swollen, shiny and warm. Your face is a little bit swollen. You have developed what is called a leprosy reaction, this is a result of increased activity of the body's immune system (that is fighting the leprosy bacteria). Go to the nearest health facility for advice and treatment. Go back to space 43.
51	The feet	<u>Sorry.</u> You had completed your treatment, but a rare thing happened: you developed leprosy again after a few years. This is very rare. Climb the ladder down to get a check-up at the health centre at space 30.

Winning the game

To win the game, a piece must land exactly on space 53 (finish). If a player throws too many, the piece counts the extra points backwards from the winning space. For example:

- If you are on space 50 and you throw six – you move three steps until space 53 and then three steps back again so you land on space 50 again (six steps in total). You will move forward again on your next throw.
- If you are on space 52 and your throw three – you move one step until space 53 and two steps back until space 51 (three steps in total). You will move forward again on your next throw.
- If you are on space 49 and you throw four – you move four steps until space 53 and win the game!

Supporting stories

Story: Vivek (week 3 and 4)

Vivek is a man who is affected by leprosy. Due to his disease, he lost some of the strength in his arms and legs. He cannot work on the land like he did before. Vivek feels useless, he can't contribute to the family. He thinks he will never be able to work again. He feels like he can never do anything right.

Story: two perspectives (week 4)

Perspective one: It was a hot and humid morning. The weather was unbearably hot that day. As if things couldn't get any worse, something unexpected happened, a punishment of God: heavy rainfall. The drops of the rain looked like rocks. Everybody on the street was wet and cold. Children walked through the muddy puddles and got their fresh clothes dirty. The streets were soaked with water. It would be impossible to do anything today. The sky looked grey and the air was humid. Rain had turned a sunny day into a dreary one.

Perspective two: It was a hot and humid morning. The weather was extremely hot that day. Suddenly, something unexpected happened, a miracle of God: heavy rainfall. The drops of the rain looked like tiny crystals. A rainbow appeared in the sky. Children were splashing and playing in the muddy puddles. You could almost see the crops on the land growing! Harvest would be amazing this year. The greenery looked refreshing. Rain had turned the dreary day into a lovely one.

Story: from impaired to proud (week 5)

A beautiful, intelligent young girl was diagnosed with leprosy in her teens. Due to late diagnosis she developed an impairment on her right hand. Two fingers had contractions. She was so ashamed, that she hid her hands and kept constant guard over it so that no one would notice it. She would not go out of the house except to go to school. After a few years she started fighting for the welfare of other people affected by leprosy. She understood the hardships they go through. She enjoyed being able to help people and she became proud of being able to help others. She told them about the shame and disability that she had experienced. Her impairment became a symbol of her victory over shame and fear, like a soldier's scar after the battle. When asked if she would like to undergo surgery to correct her impaired fingers, she refused. In her opinion, straightening her fingers would be like removing the symbol of her victory.

Story: Aparna (week 6)

Aparna is a lady who worked many years cleaning a family house. She was a widow; she was 65 years old when she started leprosy treatment. She told the woman who hired her about the treatment because she would have to miss a few days of work to go to the clinic. The woman laid her off. She could not get another job since. She tried to get one health benefit, but it did not work, for careless processing of her documents by the government staff. She moved in the back of her daughter's house because she could not afford to pay rent anymore. Her sister-in-law gives her a bag of food every month. Now she tries to make ends meet by fixing clothes that are torn, polish nails for neighbours. She does not have any impairments nor any disability as a result of leprosy. She is at the end of her treatment and is physically fine but a lot poorer than before the diagnostic.

Story: a father with leprosy (week 7)

Sunil is a rice farmer who was diagnosed with leprosy when he was 36 years old. Because Sunil was diagnosed late, he already had some visible signs of leprosy and a lot of pain. He had undergone surgery to help him walk better. After surgery he had to use a wheelchair and became very sad. He did not want to talk to anyone or go out or do anything. After a long time, he decided he had to look to God to help him with his problems. He prayed to God asking for help with his problems. Later he also told his family members that he was very sad, and they all agreed to pray. One day he heard his young son (5 years old) praying that he would get better and walk again. This encouraged him a lot. He felt much less sad. He decided to do all he could. He went to rehabilitation and he did all the exercises. Eventually his feet recovered from the surgery, and now he walks quite well and he says that God and his son helped him get better.

Story: Bishnu (week 8)

There was a family in Chhattisgarh that was known to everyone in their village. The father of the family did bicycle repairs from a small shop at the front of their house. They had four children, one daughter (Bishnu) in high school, two boys in primary school and one baby still at home. Last year, Bishnu was diagnosed with leprosy, and she has recently finished her MDT treatment. Because she was diagnosed a little bit late, Bishnu doesn't feel anything on the ends of two fingers. Sometimes Bishnu drops things when she isn't concentrating, but when she does, her mother hits her and says she is trying to avoid work. Bishnu's father also gets angry at her. He says because of her some people don't come to his shop. Sometimes he doesn't even want to have his food from the same pan as Bishnu. He says it is her fault the family is poor. Last week he said she should leave school because she isn't going to be able to do anything anyway. Her brothers also tease her and say the things they hear others say about her. Bishnu is very sad and doesn't want to go out of the house anymore. Bishnu has always tried very hard at her school work and does well, she doesn't want to miss out on her school work, but lately she has lost motivation. She thinks she is the cause of her family's problems and that they would be better off without her.

Week 1. Resilience is bouncing back from difficulties (such as discrimination)

What to bring:

- You will have to prepare for the Introduction Activity by thinking of a person you know of, who has had a lot to deal with in life, and has been able to cope and 'bounce back'. Be ready to explain to the family:
 - The name of that person
 - What did that person have to cope with?
 - What characteristics or qualities did that person have?
 - What skills did they use to overcome their problems?
 - What sources of social support did they use?
- For Activity One, you will need a big sheet of paper and some felt pens. You will draw two circles, as in the example below
- For Activity Two, you will need a big sheet of paper and some felt pens (same as activity one). You will draw two circles, but this time start with the outer circle - things we can't control – write in: natural disasters, getting diseases, problems. Then draw the inner circle - things we can control – write in: my ability to bounce back, my ability to adapt to change
- For the Introduction and Review, bring a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm, example below).

Aims: (What do we want people to learn?)

- We want to introduce the concept of resilience for persons affected by leprosy and their families
- We want people to understand that resilience is bouncing back after a major problem
- We want to explain that it relates to coping, there are things we can do to build resilience and we should know what we have the power to control and what we can't control.
- We want to introduce people to the importance of resilience

Evidence: (Why is it important to address this?)

- When people with diseases like leprosy learn resilience, they can become stronger¹
- They can deal with their emotions better ^{2,3}
- They feel better about themselves; they have better relationships, and they are more confident³
- We know that resilience can be learned by developing a few skills ^{1,2,3}

Introduction

Explain that this session:

- Will introduce the concept of resilience for persons affected by leprosy and their families
- Will help the family understand that resilience is bouncing back after difficulties like bamboo in a storm
- Will help the family understand that resilience relates to coping, and that there are things we can do to build resilience.
- Will help the family members to understand that there are some things they have the power to control and some things they can't control. Knowing the difference helps us to be more resilient.
- **To start the session, the facilitator shows the main diagram of our project** (being strong and bouncing back like the bamboo in a storm).

- **The facilitator explains** that we want people to be able to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. The first part is the roots of the bamboo. Our knowledge about resilience is like the roots of bamboo, we need strong roots to be resilient and bounce back like the bamboo. We will talk about this knowledge this week and next week.
- The point of this first session is to help people get an idea of resilience. We want people to think about people who are resilient and think about ways they might be more resilient.

The facilitator asks the family members:

Think of someone you know or admire or know of, who has had a lot to deal with in life, and has been able to cope and ‘bounce back’. This may be someone you know (a family member or a friend) or may be someone you have heard or read about.

The facilitator goes first and gives a good (practiced) example of a person who has had a lot to deal with in life and has been able to cope and ‘bounce back’. Name that person and explain to the family:

- What did that person have to cope with?
- What characteristics or qualities did that person have?
- What skills did they use to overcome their problems?
- What sources of social support did they use?

The facilitator now asks each family member to do the same. Ask the family members to describe:

- What did that person have to cope with?
For example: the person was diagnosed with a disease.
- What characteristics or qualities did that person have?
For example: a positive outlook on life, perseverance, knowledge about the disease they were diagnosed with, ability to ask for help.
- What skills did they use to overcome their problems?
For example: decision making, creativity, positive thinking, open-minded, honesty, asking for help.
- What sources of social support did they use?
For example: family, friends, neighbours, health staff.

Key messages:

- Resilience doesn't mean that bad or difficult things will never happen.
- Emotional pain and sadness are common in people who have suffered major adversity like leprosy.
- The good news is that you can learn skills and develop characteristics that help you build resilience. That is what this programme is about.
- One of the main things stopping people being resilient is that they feel like things are out of control. It is very hard to bounce back if we don't know what to do or if we feel like we are stuck
- Part of resilience is knowing what we can influence directly and what we can't. To be resilient in the face of discrimination we need to know what we can control and what we can't.

Activity 1

The purpose of this activity is to help people think about what they can influence directly and what they can't.

The facilitator explains to the family that it is very hard to be resilient when things feel like they are out of control. It is important to realise that there are many things we can't control. That is OK. However, it is also very important to realise that there are some things we can control. There are things we can influence. These are important. We should focus on those things we can influence and control.

The facilitator draws two circles:

1. The circle of things we can control or influence (inner). These are the things you can control.
2. The circle of things that affect us but that we can't control (outer). These are things you're concerned about and that affect you, but that you can't control.

The facilitator goes first and gives a good (practiced) example (but just gives one example from the below or from the diagram). Choose one from:

- **Circle of things I can control (inner)** – my attitudes, my reactions, my enthusiasm, my beliefs, how I use my free time, who I spend time with, how I support family members.
- **Circle of things I cannot control (outer)** – other people's attitudes, discrimination, other people's beliefs, other people's behaviour.
- **After you have suggested one, ask the other family members to make other suggestions**
- Discuss the examples. - Points to make
 - What is in your circle of things you can control or influence? (Discuss)
 - What is in your circle of things you can't control? (Discuss)
 - A very important part of resilience is recognising what you can influence/control and what you can't.

Key messages:

- *Resilience can come from knowing what you can control and what you can't. You are then able to make realistic plans.*
- *You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Knowing what you can change and what you can't is a good first step.*
- *We see that resilience is not anything magical, but it can be built and improved through learning about it and practicing resilience skills.*
- *Resilient people have a realistic idea of their control over themselves and situations (a sense of control).*

Activity 2

This activity is basically the same as Activity 1 but it emphasises the point that a large part of resilience comes from within us.

The facilitator, like in activity 1, draws two circles:

- The circle of things we can control or influence (inner). These are the things you can control.

- The circle of things that affect us but that we can't control (outer). These are things you're concerned about and that affect you, but that you can't control.

The facilitator then writes in each circle, this time starting with the outer circle:

- Circle of things we can't control (outer)** – write in there things like: natural disasters, getting diseases, problems.
- Circle of things we can control (inner)** – my ability to bounce back, my ability to adapt to change.
- Explain to each family members that they can't control things like natural disasters and disease, but they can control how they adapt, how they respond, how they prepare. Ask them to discuss this (For example, “Is it helpful to see the difference between things we can't control and things we can?” or “How do you feel about this?”

This is a very important discussion point. It shows the family that they are not responsible for discrimination, but they can influence how they will bounce back

- Emphasise again that a very important part of resilience is recognising what you can influence and what you can't.

Key messages:

- Resilience is about bouncing back; but it is also about adapting to change and becoming stronger.*
- If we are always critical of ourselves, thinking we will fail or feeling guilty for things we can't control, it will stop us from being resilient. We will find it hard to bounce back*
- If we take responsibility for things we can't control, we will be frustrated and we will find it hard to bounce back.*

Review

- Ask each person the family: What's one thing I know I can accomplish this week that helps me be more resilient and move in the direction I want to go? Ask each person around the family to answer.**

For example: be more aware of my own thoughts, don't take responsibility for things I can't control, my enthusiasm, how I spend my free time.

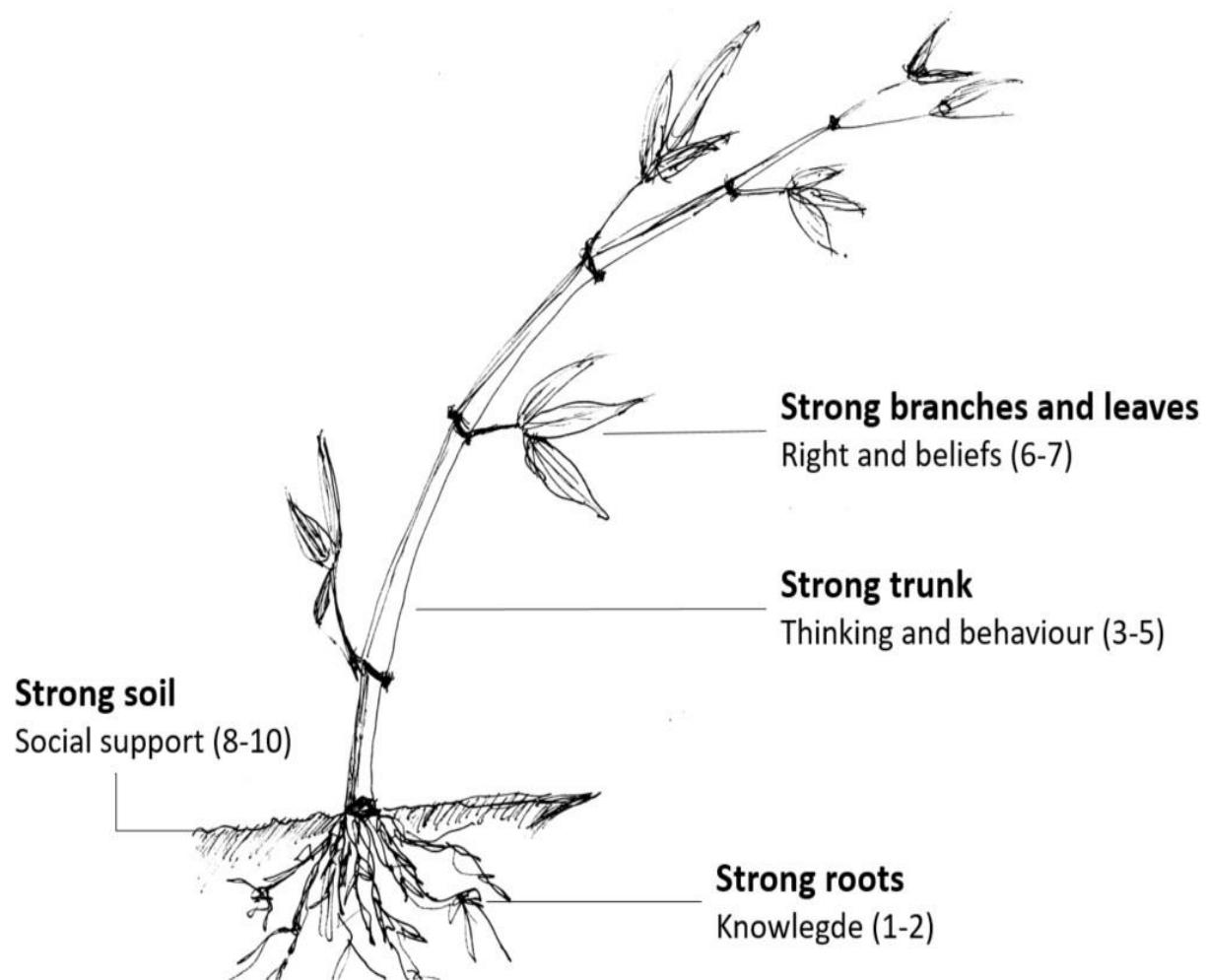
- Finish the session by showing the family the diagram of this project again (Being strong and bouncing back like the bamboo in a storm)
- Explain that there are many parts to bouncing back like the bamboo diagram. This week we have discussed the first week which is knowledge about resilience. Knowing about resilience is like the roots of the bamboo, which helps it to be strong in a storm.

Resources used:

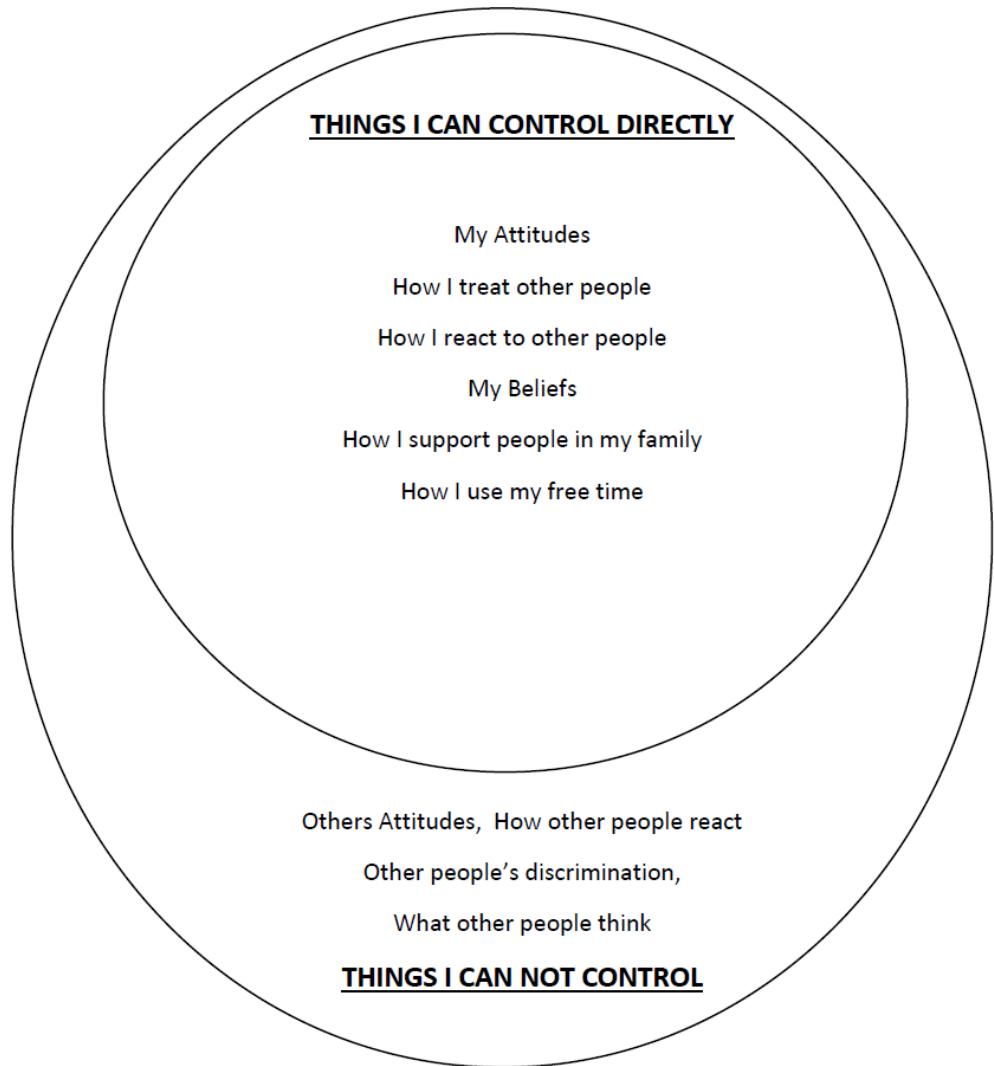
- Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2015). Stigma and racial/ethnic HIV disparities: moving toward resilience. *Stigma and Health*, 1(s), 60-74
- Van 't Noordende, A. T., Kuipers, P., Bakirtzief Da Silva Pereira, Z (2019) Strengthening personal and family resilience: A literature review for the leprosy context. *Leprosy Review*, 90, 88-104.
- Zautra, A. J., Hall, J. S., Murray, K. E., & 1, t. R. S. G. (2008). Resilience: a new integrative approach to health and mental health research. *Health Psychology Review*, 2(1), 41-64.

Strong as bamboo in a storm

Bouncing back from leprosy discrimination



Example Circles for Activity One (and adapted for Activity Two)



Week 2. Knowledge about leprosy helps us bounce back

What to bring:

- For the Introduction, bring a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- For Activity One, you need:
 - Hardcopy of the leprosy board game (A3 or A2 size, ideally glued to a piece of cardboard)
 - The rules of the board game.
 - Differently coloured pieces, one for each family member.
 - One dice.
- For Activity Two, you need the 'Flipbook' (developed by NLR).

Aims: (What do we want people to learn?)

- We want to increase the family member's knowledge about leprosy.
- We want the family to gain insight into local beliefs about leprosy.
- We want the family to think about the power of knowledge.
- We want the family to recognize the usefulness of knowledge in relationships.
- We want family to learn about sources of knowledge about health and specifically about leprosy.

Evidence: (Why is it important to address this?)

- More knowledge about leprosy is associated with lower levels of stigma.^{1,2} This suggests that improving knowledge about leprosy may also improve attitudes.
- Games offer pleasurable learning, learning through doing and learning through collaboration.³
- Board games can effectively be used for learning.⁴

Introduction

The facilitator shows the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the roots of the bamboo that keep it strong. Our knowledge about leprosy is part of that, it is like the roots that keep the bamboo alive. We need some understanding of leprosy to be resilient and bounce back like the bamboo in the face of discrimination.

The facilitator explains that this week the family is going to talk about:

- Local beliefs and facts about leprosy.
- How you can use knowledge when someone is acting badly towards you or discriminating against you.
- Important information about leprosy.

Activity 1

The facilitator asks the family members the following questions (the facilitator writes down the answers):

- **What do you think is the cause of leprosy?**

Ask each person to give an answer. The facilitator then explains that the only cause for leprosy is a bacterium. There are many diseases that caused by bacteria. Even common infection is caused by bacteria. The bacterium that causes leprosy grows very slowly, that's why it takes so long people to notice that they have leprosy.

- **What are the local beliefs in your community, about leprosy? For example what do people believe about the cause of leprosy, how it is transmitted, and how it affects a person?**

For example: people may say that leprosy transmits through touch, that leprosy is hereditary, that leprosy is a curse, that you can get leprosy when you have committed sins in a past life.

For each local belief, the facilitator asks the family whether they think this is true or false. For each local belief, the facilitator tells the family whether it is true or not.

- **What can you tell people if they think leprosy is hereditary?**

For example: There are many families with only one person affected by leprosy in the family. This is because leprosy is caused by a bacterium. Leprosy is easily curable; medication can kill the bacteria in six to twelve months and after that you are completely cured.

- **What can you tell people if they think leprosy transmits through touch?**

For example: Why do most health workers not have leprosy? Leprosy is not easily transmissible! You can invite people to talk to a health worker or invite a health worker or ASHA to the village to explain about leprosy.

The facilitator explains about leprosy using the Flipbook (NLR/NLEP) after all questions have been discussed. **The facilitator goes through each page of the Flipbook and explains all images.** The family members are invited to comment and ask questions.

Activity 2

The facilitator explains that the family is going to play a game. **The facilitator reads and explains the rules of the game to the family.** The facilitator verifies whether all family members have understood the rules of the game.

The family plays the game for approximately 30 minutes.

After that, the facilitator asks the family what they've learned about leprosy while playing the game.

For example:

- The early signs of leprosy are skin patches that have no sensation.
- Leprosy is not contagious after a person has taken at least one dose (or completed) MDT treatment.
- Leprosy is a disease like any other disease.
- Leprosy is only caused by bacteria
- Leprosy is not easily passed from one person to another
- Leprosy medication is free of charge and available at the health centre and government hospital.
- Leprosy treatment takes six to twelve months, after that you are completely cured.
- We should support people affected by leprosy.

- *If people get treated early, it will prevent disabilities.*
- *It is possible to get reconstructive surgery if you have serious problems.*
- *If a few patches have become red, swollen, shiny and warm you should report to the health facility, it may be caused by your body fighting the leprosy bacteria.*

Key message: knowledge is power.

The facilitator asks the family to reflect on how knowledge can be used to help us to be resilient and in the face of discrimination, when the game is finished - how to bounce back like bamboo in a storm. The facilitator asks the following questions:

- **What did you think of the game? What did you like and what didn't you like?**
- **How can you help other people with what you know about leprosy?**
For example: identifying early symptoms of leprosy on other people, helping them get treatment, early treatment will result in less or no visible impairments.
- **How can what you've learned (knowledge about leprosy) help you to bounce back, to be stronger?**
For example: if people say bad things about persons affected by leprosy, you can tell them the facts about leprosy. Many people are afraid of leprosy because they do not understand the disease. Leprosy is not very contagious!

Review

The facilitator asks:

- **What did you learn about leprosy today?**

Resources used:

1. Van 't Noordende, A. T., Korfage, I. J., Lisam, S., Arif, M. A., Kumar, A., & van Brakel, W. H. (2019). The role of perceptions and knowledge of leprosy in the elimination of leprosy: A baseline study in Fatehpur district, northern India. *PLoS Neglected Tropical Diseases*, 13(4), e0007302-e0007302.
2. Seshadri, D., Khaitan, B. K., Khanna, N., & Sagar, R. (2014). The tangled web: a study of knowledge and attitude towards leprosy from a tertiary care hospital in India. *Indian J Lepr*, 86, 27-41.
3. Kirriemuir, J., & Mcfarlane, A. (2004). Literature Review in Games and Learning. A NESTA Futurelab Research report-report, 8.
4. Ramani, G. B., Siegler, R. S., & Hitti, A. (2012). Taking it to the classroom: Number board games as a small group learning activity. *Journal of educational psychology*, 104(3), 661.

Week 3. A positive view of ourselves helps us bounce back

What to bring:

- For the Introduction, bring a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- For Activity One, you need to bring a printed version of Vivek's story (included in the boxes below).
- In this week, you should use your phone to take a photo of the family all together. Please print a colour copy of this photo for later (we will give each family a copy of this printed picture in the last week of the program - the social gathering).

Aims: (What do we want people to learn?)

- We want people to gain insight into how they see themselves and others.
- We want the family to recognise character strengths in themselves and others.
- We want the family to understand more about factors that can contribute to resilience.
- We want the family to build awareness of their own thoughts and how thoughts can influence emotions and behaviour.
- We want people to practice positive self-talk in a way that builds resilience.

Evidence: (Why is it important to address this?)

- Experiences of stigma can lead to people internalizing stigma, avoiding others, and becoming anxious.¹
- If people avoid others, they become lonely and anxious.²
- If they internalize stigma, they have low self-esteem, are unsure of themselves and have poor quality of life.^{2,3}
- It is important to prevent internalized stigma and to promote positive self-esteem.³
- Positive self-esteem (feeling of self-worth) and self-efficacy (belief in one's own ability) are vital to resilience and build enthusiasm and reduce guilt and worry.³
- Being kind to yourself is also vital to resilience.^{4,5} It promotes optimism and positive change.
- Identifying and building on strengths is an excellent way to build resilience and be our best selves.⁶

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the stem or the trunk of the bamboo that keeps it strong. Our understanding and view of ourselves is like the stem or trunk that keeps the bamboo upright. We need a clear, confident understanding of ourselves to be resilient and bounce back like the bamboo.

The facilitator explains that this week the family is going to:

- Look at how the family members see themselves and their family members
- Look at what they like about their family members
- Look at how self-esteem and being nice to yourself can help you to be resilient.

The facilitator explains that the family is going from “we can’t” to “we can”!

Activity 1

The facilitator explains that s/he will read a story. The facilitator explains that after s/he reads the story, s/he will ask the family a few questions. **The facilitator reads the following story:**

- Vivek. Vivek is a man who is affected by leprosy. Due to his disease, he lost some of the strength in his arms and legs. He cannot work on the land like he did before. Vivek feels useless, he can't contribute to the family. He thinks he will never be able to work again. He feels like he can never do anything right.

The facilitator now discusses the following questions with the family. If the facilitator thinks it is necessary, s/he can read the story again. Remember to give each person time to respond.

- **Imagine Vivek is your friend. Vivek is struggling. How would you respond to your friend Vivek (the person in the story) in this situation? What would you say to him? Would it be different from what Vivek is telling himself?**

For example: I am sorry that this happened to you. You are not useless, you can do other things, I still like you as a friend. Maybe I can help?

- **Now imagine it is you in the story – imagine you are the person in the story or think about times when you felt bad about yourself or were struggling. How do you typically respond to yourself in these situations? Are you as critical of yourself as Vivek?**

For example: maybe you would also think you are useless and think that you can never do anything right?

- **Did you notice a difference between how Vivek talks to himself and how you would talk to Vivek? If so, why do you think you treat yourself and others differently?**

For example: usually, the way we treat ourselves and talk to ourselves is different from how we treat a friend. We are usually much nicer to our friends. We tend to be very critical of ourselves.

- **How do you think things might change if you responded to yourself in the same way you would respond to a close friend? What would happen if we were to treat ourselves in the same way we treat a good friend when he or she is in a difficult situation?**

For example: Notice that it's easy to give our friends love, compassion, and understanding, even when they fail or make a mistake. Why is it so much harder to extend that same understanding and compassion to ourselves when we make a mistake? We would feel better if we would treat ourselves in a nicer way. The situation might now change, but how we feel about it will change.

The facilitator reflects upon the following:

We can look at a situation in different ways. How we view a situation is influenced by our current point of view. Our interpretations of our stories and events will change as we grow and mature. Knowing that our interpretation can and will change, gives us the faith and hope that things can feel better tomorrow.

Key messages:

- *It's natural for us to be kind to the people we care about. We reassure them of our respect and support when they're feeling bad about themselves. We comfort them when they're going through hard times. Most of us are quite skilled at being kind, understanding and compassionate to those we care about. We also need to be compassionate to ourselves. To*

realize the benefits of self-compassion, therefore, all you need to do is turn around and apply those same skills toward yourself. It could change your life.

- *Perfection is an unrealistic goal. Everybody makes mistakes, you learn from them. Nobody is perfect and that's fine.*
- *Nobody has complete control over every aspect of their life.*
- *Life is full of challenges. We can't avoid all challenges, but we can remain open, flexible, and willing to adapt to change.*
- *Focus your energy on identifying the things that are within your control and seeing what you can do about them. Your actions and decisions shape your life.*
- *Stop comparing yourself to other people. If you compare yourself to other people, there will always be those who are better, and those who are worse. If you always want what others have, you will never have enough. You will always want more. That's an endless cycle, and it will never lead to happiness.*

Activity 2

The facilitator explains that the next exercise the family is going to do is to look at each other strengths and what they like about each other. Focusing on one person in the family at a time, the group talks about all things they like about him or her. If the family members say the same thing, they like about a family member too many times, the facilitator may ask them to think about something else they like about him/her, to get a variety of strengths.

- **The facilitator starts with an example and explains what s/he likes about his/her spouse or good friend.**

For example: funny, sweet, intelligent, always ready to help, loving, can do nice things together, have fun together.

- **The facilitator then asks each family member to say at least one thing they like or appreciate about the other family members – focusing on one family member at a time (what do you like or appreciate about him/her? What is s/he good at?)**

In the end, all family members should have been 'discussed'.

Examples for the facilitator:

- | | | |
|-----------------|-----------------------|---------------|
| • Enthusiastic | • Kind / friendly | • Wise |
| • Hard-working | • Patient | • Polite |
| • Reliable | • Sincere / honest | • Forgiving |
| • Responsible | • Thoughtful | • Courageous |
| • Considerate | • Intelligent / smart | • Generous |
| • Creative | • Understanding | • Optimistic |
| • Funny / witty | • Loyal | • Serious |
| • Helpful | • Truthful | • Adventurous |
| • Charming | • Sociable | • Fearless |

The facilitator emphasizes that all family members have a lot to offer and a lot to be happy about. The group then discusses the following:

- **If a bad situation happens, (mistake, failure, rejection, criticism) does it take away someone's good qualities? For example, if someone is affected by leprosy – is s/he still funny/hardworking/friendly/intelligent?**

For example: a bad situation does not take away someone's good qualities.

- **How can these good qualities / strengths help you to be more resilient?**

For example: resilient people understand that setbacks happen and that sometimes life is hard and painful. They still experience the emotional pain, grief, and sense of loss that comes after a tragedy, but their mental outlook allows them to work through such feelings and recover. Resilient people are able to utilize their skills and strengths to cope and recover from difficulties in ways that foster strength and growth. In many cases, they may emerge even stronger than they were before

Key messages:

- **Resilient people are able to utilize their skills and strengths to cope and recover from problems and challenges.**
- **Social support is another critical variable that contributes to resilience.** Mentally strong people tend to have the support of family and friends who help bolster them up in times of trouble. Talking about the challenges you are facing can be an excellent way to gain perspective, look for new solutions, or simply express your emotions.
- **Improving self-esteem requires work.** It involves developing and maintaining healthier emotional habits but doing so, will provide a great emotional and psychological return on your investment.

Review

The facilitator asks:

- **How did it feel to say something nice to your family members?**
- **How did it feel when someone else said something nice about you?**
- **What did you learn about yourself this week?**

The facilitator uses his or her phone to take a photo of the family all together.

Reason (not to be shared with the family yet): we will give the family a copy of this picture in the last week of the program - the social gathering.

Resources of this week:

5. Zhang, L., Li, W., Liu, B., & Xie, W. (2014). Self-esteem as mediator and moderator of the relationship between stigma perception and social alienation of Chinese adults with disability. *Disability and health journal*, 7(1), 119-123
6. Morgades-Bamba, C. I., Fuster-Ruizdeapodaca, M. J., & Molero, F. (2019). The impact of internalized stigma on the well-being of people with Schizophrenia. *Psychiatry research*, 271, 621-627.
7. Post, F., Pardeller, S., Frajo-Apor, B., Kemmler, G., Sondermann, C., Hausmann, A., ... & Hofer, A. (2018). Quality of life in stabilized outpatients with bipolar I disorder: Associations with resilience, internalized stigma, and residual symptoms. *Journal of affective disorders*, 238, 399-404.
8. https://self-compassion.org/what-self-compassion-is-not-2/?mbid=social_huffpo
9. Trompetter, H. R., de Kleine, E., & Bohlmeijer, E. T. (2017). Why does positive mental health buffer against psychopathology? An exploratory study on self-compassion as a resilience mechanism and adaptive emotion regulation strategy. *Cognitive therapy and research*, 41(3), 459-468.
10. <https://positivepsychology.com/resilience-activities-worksheets/>
11. Taken from https://self-compassion.org/wptest/wp-content/uploads/self_compassion_exercise.pdf

12. Taken from <https://self-compassion.org/self-compassion-treating-yourself-as-youd-treat-a-good-friend/>

Week 4. Positive ways of thinking help us bounce back

What to bring:

- For the Introduction, bring a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- For the Introduction, also bring a cup to be filled with water.
- For Activity One, you will need a printed version of ‘two perspectives’ story about the rain (story one and story two below).
- For Activity Two, you will need a printed version of Vivek’s story (below).
- For the Review, bring a pen and paper to write down the ‘messages of gratitude’. You will also need to bring a pen and paper for each participant for the homework exercise.

Aims: (What do we want people to learn?)

- We want people to recognize how thoughts can affect the ability to cope with situations.
- We want the family to identify, regulate and challenge negative and counterproductive thoughts that hinder resilience.
- We want the family to identify and challenge “thinking traps” such as jumping to conclusions. Keep things in perspective and context.
- We want people to practice cognitive restructuring, reframing and self-regulation of emotions, thoughts and behaviours.
- We want the family to practice being grateful and recognize the benefits of being grateful.

Evidence: (Why it is important to address this)?

- There are cognitions or thoughts that are classified into negative automatic thoughts and dysfunctional or irrational beliefs. Negative automatic thoughts are thoughts or images that occur in specific situations when a person feels threatened in some way. Dysfunctional or irrational beliefs are assumptions that individuals have about the world, the future, and themselves. These beliefs provide a schema that determines how a person may interpret a specific situation.¹
- Challenging irrational thoughts can be done by evaluating and testing the evidence for and against a particular assumption. With practice, more accurate thinking becomes the automatic mode of response. The goal is to test people’s thoughts and if necessary, to modify them in order to get a more realistic perspective about the real world.¹
- Research has shown that people with pessimistic thinking styles are at greater risk for depression than people who have a more optimistic view of life.²
- Three effective strategies used to challenge counterproductive beliefs are evidence, optimism, and perspective.²
- Research has shown that frequently acknowledging and expressing gratitude is associated with higher satisfaction with life and wellbeing.^{2,3,4} People who are grateful also suffer from reduced symptoms of depression.¹ In addition, gratitude may function to promote relationship formation and maintenance.⁵

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the stem or the trunk of the bamboo that keeps it upright. Our ways of

thinking are like the stem that keeps the bamboo upright. We need strong ways of thinking to be resilient and bounce back like the bamboo.

The facilitator explains that this week the family will:

- Look at how our thoughts influence how we feel and behave.
- Explore what all family members are grateful for and how this relates to how you feel.
- Look at what thoughts, feelings and behaviour help us to cope with situations and 'bounce back'.

The facilitator fills a cup with water, until it is half full. If the facilitator still has a cup of tea in his/her hands, this can also be used. The facilitator asks the family members to raise their hand if they think the cup is half full. The facilitator then asks the family members to raise their hand if they think the cup is half empty. S/he then explains that you could also consider the cup completely full: half of it is water, half of it is air. The facilitator explains that there are multiple ways to look at (the same) thing and that there is not one right way to look at things (not one 'truth').

Activity 1

The facilitator explains that s/he will read two stories. The stories describe the same situation, but the situation is experienced differently in both stories. The facilitator explains that after s/he read the stories, s/he will ask the family a few questions.

The facilitator reads story one.

- **Story one:** It was a hot and humid morning. The weather was unbearably hot that day. As if things couldn't get any worse, something unexpected happened, a punishment of God: heavy rainfall. The drops of the rain looked like rocks. Everybody on the street was wet and cold. Children walked through the muddy puddles and got their fresh clothes dirty. The streets were soaked with water. It would be impossible to do anything today. The sky looked grey, and the air was humid. Rain had turned a sunny day into a dreary one.

The facilitator now reads story two.

- **Story two:** It was a hot and humid morning. The weather was extremely hot that day. Suddenly, something unexpected happened, a miracle of God: heavy rainfall. The drops of the rain looked like tiny crystals. A rainbow appeared in the sky. Children were splashing and playing in the muddy puddles. You could almost see the crops on the land growing! Harvest would be amazing this year. The greenery looked refreshing. Rain had turned the dreary day into a lovely one.

After the stories have been shared, the impact of negative and positive thoughts is discussed. **The facilitator explains that how we interpret events impacts how we react to them.** Both positive and negative emotions are a part of life. It can help to look at situations from multiple perspectives. The following is discussed:

- **What is the difference between the first and the second story?**

For example: the first story is very negative; the second story is positive.

- **What do you think happens if you always only look at the negative things in life?**

For example: you can't see the good things in life. For example, in story one the person could not see that the children in the streets were enjoying themselves. The person also didn't see the rainbow. When we're absorbed in what's wrong, we're unable to notice what's right in our life.

- **How can it help us to look at things in a more positive way?**

For example: it makes us feel better if we look at the positive things in life. We experience the world in a more positive way. We can see the rainbow in the rain.

Key messages:

- *There are positive and negative thoughts, they can be helpful or unhelpful.*
- *It's normal to have negative thoughts. However, negative thought patterns can be repetitive and are usually not helpful. They can cause unwanted or unpleasant emotions like anxiety, stress, fear, unworthiness, shame etc.*
- *When we're absorbed in what's wrong, we're unable to notice what's right in our life.*
- *As can be seen in the 'two perspectives' story, our thoughts are not 'the truth'. Our thoughts are just thoughts, not reality. Our mind determines and shapes how we see the world, ourselves and our life and how we view others. If we use more positive thoughts, we will be able to experience the world in a more positive way.*

Activity 2

A negative experience and negative thoughts are discussed. The facilitator explains that s/he will read a story, the same story that was also read in the week/session about 'self-esteem'. The facilitator explains that after s/he read the story, s/he will ask the family a few questions. **The facilitator reads the following story:**

- Vivek. Vivek is a man who is affected by leprosy. Due to his disease, he lost some of the strength in his arms and legs. He cannot work on the land like he did before. Vivek feels useless, he can't contribute to the family. He thinks he will never be able to work again. He feels like he can never do anything right.

The facilitator asks the following questions that are discussed in the family. If the facilitator thinks it is necessary, s/he can read the story again.

- **What negative thoughts does Vivek have?**

For example: unable to work, she feels useless, will never work again, can never do anything.

- **Do you think what Vivek tells himself is true? Does he have any evidence? Why is it true (or not)?**

For example: Vivek may be unable to work now, but maybe he can work again in the future. Instead of working on the land, he may be able to do other things that require less strength in his arms or legs. He is not useless; he just has to adapt to the new situation.

- **Are Vivek's thought useful or helpful? Does it help if Vivek thinks he is useless? Will that make the situation better? Will it give him strength?**

(No)

- **How can Vivek make the best of this situation? What other things could Vivek do if he cannot work on the land?**

For example: work in the house, help his family members with other chores, spend time with friends.

- **How would you respond if a friend spoke about himself that way?**

For example: you would say it is not that bad, he could do other things, it is only temporary. Maybe you would offer your friend help.

The facilitator explains that the family will try to change Vivek's negative thoughts into more helpful and adaptive responses. **The facilitator asks:**

- **What could Vivek say to himself?**

For example: OK, I can't work now. It is only temporary. There are other things I can do. I can work around the house. Things could have been worse.

- **As a last step, the family tries to look on the bright side and see if there is anything Vivek can be grateful for. What could Vivek be grateful for?**

For example: that there are medicines that can completely cure his disease, that there are things he can still do, that he gets to spend more time around the house with people who are close to him.

Key message:

- ***There are positive and negative thoughts. It's normal to have negative thoughts. However, negative thoughts are usually not so helpful. Positive thoughts are usually helpful. It takes effort and exercise to change your negative thoughts into more positive ones, but it can be done!***

Review

The facilitator introduces and explains the family's homework that is about being grateful. Feeling thankful can improve health in both direct and indirect ways. Acknowledging the good in life has a tendency to make positive emotions, such as joy and contentment, stronger. Practicing gratitude can also make you better equipped to handle the difficulties of life that may arise. **The facilitator first shares a story of what s/he is grateful for today.** The facilitator then asks the group the following questions, that are briefly discussed:

- **What can you be grateful for in this moment?**

For example: family, friends, achievements, where you live, the weather.

- **Why are you grateful to your family?**

For example: because they helped you with something, they're always there, you love them, they make you laugh, they cook great food and prepare amazing tea.

The facilitator now explains the homework: every day until the next resilience day, all family members will write down one thing each day that they are grateful for or things that went well each day. If participants are unable to write, they are asked to make a small drawing and if that is not possible, they are asked to remember. The purpose of the exercise is to reflect on the past week and remember things you are especially grateful for. In this way, you are focusing on all the good things that happened to you in a given set of time. All participants are given a small journal and a pen. The facilitator explains that they will discuss what the participants are grateful for in the next session/week.

Resources used:

1. Hofmann, S. G., & Asmundson, G. J. (2008). Acceptance and mindfulness-based therapy: New wave or old hat?. *Clinical psychology review*, 28(1), 1-16.
2. Reivich, K. J., Seligman, M. E., & McBride, S. (2011). Master resilience training in the US Army. *American Psychologist*, 66(1), 25.
3. McCanlies, E. C., Gu, J. K., Andrew, M. E., & Violanti, J. M. (2018). The effect of social support, gratitude, resilience and satisfaction with life on depressive symptoms among police officers following Hurricane Katrina. *International journal of social psychiatry*, 64(1), 63-72.

4. Wood, A. M., Froh, J. J., & Geraghty, A. W. (2010). Gratitude and well-being: A review and theoretical integration. *Clinical psychology review*, 30(7), 890-905.
5. Algoe, S. B., Haidt, J., & Gable, S. L. (2008). Beyond reciprocity: Gratitude and relationships in everyday life. *Emotion*, 8(3), 425.

Week 5. Accepting our (changing) body help us be tall and flexible when we face pain, limitations and shame

What to bring:

- For the Introduction and Review, bring a copy of the main diagram of our project (being strong and bouncing back like the bamboo in a storm)
- For Activity Two, you will need to bring a printed copy of the 'From Impaired to Proud' story, available below.

Aims: (What do we want people to learn?)

- We want to promote insight into bodily change as a normal thing in life.
- We want to get people to consider different attitudes one might have about the same bodily trait and their implications for their wellbeing, their happiness.
- We want to stimulate accepting change and difference.
- We want to stimulate bodily care (self and others).
- We want people to start focusing on the things their body can physically do instead of those it's currently unable to do.

Evidence: (Why is it important to address this?)

- If we develop new ways to look at ourselves, especially learning to value our body: its appearance and abilities, it helps us to be more resilient¹.
- If we have self-acceptance (in the case of disabilities) this will contribute to our mental wellbeing²
- We should take care of ourselves and not ignore changes to our bodies, because that may our physical impairments worse.³
- Accepting and coming to terms with these many changes to our bodies over the lifespan is important for our mental wellbeing.⁴

Introduction

The facilitator shows the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the stem or the trunk of the bamboo that keep it upright. How we understand leprosy-related changes to the body is like the stem. We need a healthy understanding of our body to be resilient and bounce back like the bamboo.

The facilitator explains that today the family is going to talk about:

- The body, especially how we cope with changes to the body.
- Normal changes the human body undergoes during the lifespan.
- The changes we have been through and how we have adapted to them.
- Accepting some things in order to be more resilient.

Activity 1

The facilitator explains that we all undergo changes during our life span. **Change is a normal part of being alive.**

The facilitator explains that change is a normal aspect of being alive. When a child grows up we are very happy when we see the changes they go through and their new abilities. When they learn how to crawl, to walk, run, climb trees, speak, play with their brothers and sister, it is all a reason for joy and pride of the parents. And life goes on and the longer they live the more they change. They become taller, stronger, smarter, faster, and they became grownups.

The facilitator explains that although parents feel happy to see their children develop, the child often does not see how fortunate change is. We see children complaining about (growth) pain in their bones as they grow, because they are only considering the pain and do not appreciate the fact that they are becoming bigger and stronger. The same happens to us adults, when our hair becomes grey, we complain that we look old and grey. But some people think that grey hair is a symbol of wisdom and prefer letting their grey hair remain grey instead of applying henna to it.

There are multiple ways of seeing change our bodies go through. The family discussed the following questions that are asked by the facilitator:

- **The facilitator asks the family to think of the bodily changes regular people go through in life, from the moment they are born until the day they die.** The facilitator looks around the room and identifies people who are at different moments in life: a child, an adult, an old person. *If you have people of different age groups, you may point the questions to them as an example. In case there are not different age groups you may suggest they consider a child, an elderly person, a pregnant woman, an adult male.*
- **What can a one-year-old child physically do?**
For example: a one-year-old child is able to eat a banana without help. It can crawl, it might walk a little unstable.
- **What can a one-year-old child physically not do?**
For example: it cannot talk, read, write, it cannot take care of itself without the presence of an adult or an older child.
- **How is a one-year-old child different from a baby, three months old? Is there an increase/decrease in ability/ strength?**
For example: it does not breast feed anymore, it does not sleep most of the day, it is stronger, it can hold its head, it can go around the house, it can play.
- **How about a 15-year-old boy? What can he do, compared to a young child?**
For example: he does not crawl, but can walk, he eats a lot, he is stronger, he can (learn to) read, he can go to school and even work, he can play.
- **Is it easy to be a 15-year-old boy? What might be some of his physical challenges?**
For example: Many teen age boys are thin, they feel ashamed of being disproportional, they have pimples on the face as they are growing a beard, they complain about their looks, they might be concerned about their hair, their face, etc.
- **How about a pregnant woman? How is her body different from before being pregnant?**
For example: she is heavier, her clothes do not fit, she feels more tired, she feels back pain, there is a tiny human growing inside of her.

The facilitator asks each family member to give answers to these questions and welcomes other examples that illustrate changes due to normal life development.

Key messages:

- *The body is constantly changing (life cycle- from childhood to adulthood and death).*
- *Adapting to change implies doing things differently.*
- *Accepting change helps you become happier and feel good about oneself.*

Activity 2

The purpose of this activity is to help people think about the bodily changes that we all go through and that we all must learn to accept. There are things we can influence. Our attitudes about our bodies can be changed.

The facilitator tells the story “From impaired to proud”:

A beautiful, intelligent young girl was diagnosed with leprosy in her teens. Due to late diagnosis, she developed an impairment on her right hand. Two fingers had contractions. She was so ashamed, that she hid her hands and kept constant guard over it so that no one would notice it. She would not go out of the house except to go to school. After a few years she started fighting for the welfare of other people affected by leprosy. She understood the hardships they go through. She enjoyed being able to help people and she became proud of being able to help others. She told them about the shame and disability that she had experienced. Her impairment became a symbol of her victory over shame and fear, like a soldier’s scar after the battle. When asked if she would like to undergo surgery to correct her impaired fingers, she refused. In her opinion, straightening her fingers would be like removing the symbol of her victory.

The facilitator discusses the story asking:

- **What changed in the body of the girl?**

Example of answer: she became a grown woman, her fingers on her hand became hard and curved.

- **How did she react to the change?**

Example of answer: She felt ashamed, she would hide her hand, she would avoid people, she avoided going out.

- **How did she feel about herself?**

Example of answer: her impaired hand overshadowed all her life. She was not happy anymore and did not notice her good features, for example her beautiful hair, beautiful eyes, that she was young and beautiful.

- **Did her hands change over time, when she became a grown woman?**

Example of answer: No. Her hands changed because of leprosy.

- **How did her acceptance of her body/impairment help her become a happier person?**

Example of answer: she accepted herself with her impaired hand and this acceptance helped her accept others who had similar hands or even more severe physical impairments. This acceptance of others created a circle of people around her that became her friends and who admired her. She tried to see the positive things about herself: she didn’t look at her hand as an impairment, but as a (positive) “victory scar”.

- **What might have happened if she did not accept her hand and just kept isolated in her home? Would she be happy?**

Example of answer: she would not have met other people; she would not find out that her impaired hand was a bridge to meet other people and broaden her circle of friends. She would not find happiness as she did.

Key messages:

- *It is important to accept the changes that leprosy causes in our bodies.*
- *Many things about our body we cannot change - but instead of dwelling on the things we can't change, we should try to accept them for what they are.*
- *Nobody is 'perfect', part of being human is having 'imperfections' being them due to leprosy or other reasons.*

Review

The facilitator asks the family:

- **What's one thing about your body that you know you can do well and how can this help you be resilient? (Have a brave attitude about your everyday life)**

Finish the session by reminding them about the bamboo. By accepting that the wind blows and bending, instead of resisting, the bamboo bounces back up. The same happens with our changing bodies, as we accept our bodies we become stronger.

Resources used:

1. <https://www.heretohelp.bc.ca/infosheet/body-image-self-esteem-and-mental-health>
2. <https://onlinelibrary-wiley-com.eur.idm.oclc.org/doi/full/10.1111/jpm.12513>
3. Butler, Nancy. (1997) Leprosy. In: *Cambridge Handbook of Psychology, Health and Medicine*
4. Baum, Andrew; Newman Stanton; Weinman, John; McManus, Chris; West, Robert. Cambridge: Cambridge University Press, pp.521-527.
5. Papalia [Diane E.](#), Olds [Sally Wendkos](#), Feldman [Ruth Duskin](#) (1998) *Human Development*.7Ed. Mc Graw Hill. 752 pages.

Week 6. Knowing our rights can help us be strong and bounce back

What to bring:

- For the Introduction, bring a copy of the main diagram of our project (being strong and bouncing back like the bamboo in a storm)
- For Activity One, you need to bring four envelopes: Envelope one contains one small stick or toothpick. Envelope two contains two small sticks or toothpicks. Envelope three contains three small sticks or toothpicks. Envelope four contains four small sticks or toothpicks.
- For Activity Two, you need to bring a printed copy of the Story of Aparna, the 65-year-old widow who lost her job.
- For Review, bring one folder about disability benefits (Disability ID).

Aims: (What do we want people to learn?)

- We want to introduce people to the importance of knowledge about rights as needs addressed and enforced by the law.
- We want people to understand that there are social rights that alleviate inequalities that are due to life situations such as being a child, an elderly person, a person with disabilities, a person undergoing severe health problem or poverty, unemployment, etc.
- We want people to understand that there are rights that apply to each one of us be it today, or in the past or in the future or at a specific situation.
- We want people to understand how to access/enforce rights.

Evidence: (Why is it important to address this?)

- If people get diseases like leprosy they have the right to be treated differently to compensate for their not being able to exercise the right to equality.^{1,2,3}
- If the government of India guarantees the right of equality no one can be discriminated.⁴
- If rights are interrelated to needs, and leprosy affected persons have specific needs, they also have special rights.⁵

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the leaves of the bamboo that help it to grow. Our understanding of our rights and planning for the future are like the leaves of the bamboo.

The facilitator explains that this week the family is going to:

- Help people get an idea of rights.
- Discuss the importance of having knowledge about rights: what they are and how to access them.
- Introduce the concept of rights as the government response to people's needs in general, and in specific for persons affected by leprosy and their families.

Activity 1

The purpose of this activity is to help people think about needs a group of people have.

The facilitator explains:

- All governments around the world have laws that are meant to define the rights that people should have. This is also true of India, there are some rights for all Indians, without distinction. These are the **fundamental rights**. In India there are six: right to equality, right to freedom, right against exploitation, right to freedom of religion, cultural and educational rights, right to constitutional remedies⁵.

The facilitator explains:

- Despite these rights, in many cases, people's social situations differ greatly. We call that "inequalities", where their social situations are not equal.
- The way people view or treat people with leprosy can cause great disadvantage. Some look down on people affected by leprosy and treat them badly. This is a serious problem. It goes against the first fundamental right of all people in India, which is the **right to equality**.
- The facilitator asks if there are any questions so far.

The facilitator should pause for a few minutes and be available to clarify the questions that the family members might have thus far, before moving to the exercise.

The facilitator invites people to participate on an exercise about inequalities:

- Facilitator distributes four envelopes, one to each participant.

Facilitator gives the following instructions:

The person who was given the envelope with 4 sticks, stands close to the door;
The person who was given the envelope with 3 sticks, stands a step behind the person at the door;
The person who was given the envelope with 2 sticks, stands a step behind the person who has 3 sticks;
The person who was given the envelope with 1 stick, stands a step behind the person who has 2 sticks;

Facilitator says: "let's imagine that the door is the door to school (and learning), and that the sticks are examples of opportunities" ...

Waits for the family to imagine, or ask question, to clarify.

Facilitator asks the group the following questions for reflexion, while giving people time to think about a response:

- **Which person is more likely to be able to get benefits of schooling of these four people?**
Example of answer: the one with 4 sticks.
- **Is education a fundamental right for everybody in India?**
Example of response: YES.
- **How come some people have little or no opportunities for education if it is a fundamental right?**

Example of response: because they are poor, they have to work and can't go to school, because they were too far away, because they have a disability, because they are discriminated against, etc.

The facilitator concludes by saying: so, you are saying that those with more opportunities are those more likely to gain education?

The facilitator makes the point that in India, education is a right, so it should be offered to everyone regardless of their opportunities. In that case the school should allow all people in regardless of the number of sticks they hold.

Facilitator gives the following instructions:

Now everybody stand shoulder to shoulder the same distance from the door, regardless of how many sticks you have.

The facilitator explains that In India there are laws that say we all have rights and that these are more important than the inequalities that may exist between people. This is a way that guarantees the enjoyment of all fundamental rights by everyone.

The facilitator explains the following:

- In this example we saw that some people have less access to the right of education because they may have fewer opportunities.
- The fact that people are not able to enjoy their rights is called a “violation of their fundamental rights”.
- We should be able to remind people of our fundamental rights.

Key messages:

- *Rights are more important than opportunities*
- *Discrimination because of leprosy, disability, religion, gender, poverty, caste, etc are violations of the right to equality.*

Activity 2

The facilitator tells the story of Aparna:

- Aparna is a lady who worked many years cleaning a family house. She was a widow; she was 65 years old when she started leprosy treatment. She told the woman who hired her about the treatment because she would have to miss a few days of work to go to the clinic. The woman laid her off. She could not get another job since. She tried to get one health benefit, but it did not work, for careless processing of her documents by the government staff. She moved in the back of her daughter's house because she could not afford to pay rent anymore. Her sister-in-law gives her a bag of food every month. Now she tries to make ends meet by fixing clothes that are torn, polish nails for neighbours. She does not have any impairments nor any disability as a result of leprosy. She is at the end of her treatment and is physically fine but a lot poorer than before the diagnosis.

The facilitator asks:

- **What needs does Aparna have?**

Example of response: job, food, housing, retirement, leprosy treatment.

- **Are there people you know who have some of this Aparna's needs?**

Example of response: Yes. we have need of food, job, leprosy treatment, education.

The facilitator reminds the family about the exercise on inequalities and explains that the main problem Aparna faced was a result of an act of discrimination, the employer did not treat her equally as before she had leprosy. Aparna did not become a worse person because of leprosy, she continued cleaning and cooking the same as before.

The facilitator asks:

- **Are any of the needs Aparna has addressed by the “fundamental rights” in India?**

Example of response: YES - The right to be treated equally as others. This means that the employer should not have laid her off because she was sick;

- **What can Aparna do about it?**

Example of response: Could she ask for her rights from her employer? Since she is old, does she have a right to a pension?

Key messages:

- We all have rights.
- We should know our rights.
- We should seek our rights when they are not being enforced.
- Knowledge about rights makes us stronger to bounce back from the impact of leprosy.

Activity 3⁶

The facilitator explains that the family is going to talk about human rights. The facilitator explains that human rights are the basic rights and freedoms that belong to every person in the world, from birth until death. Human rights apply to everyone, regardless of where you are from or what you believe. They can never be taken away. Sometimes human rights are restricted – for example if someone breaks the law. Our human rights are based on shared values like dignity, fairness, equality, respect and independence. These values are protected by law.⁷

The facilitator asks the following questions (these questions may need extra probing):

- **Who has human rights?**

Answer: absolutely everyone. For example: criminals, children, men, women, people from India, people from Pakistan, refugees, teachers, people from all casts and persons affected by leprosy!

- **Do poor people also have human rights?**

For example: yes, absolutely everyone has human rights.

- **Do persons affected by leprosy also have human rights?**

For example: yes, absolutely everyone has human rights. People affected by leprosy are humans too. The power of human rights lies in the very fact that they treat everyone as equal.

- **Who do you think looks after human rights?**

This question is difficult and may need extra probing. Examples of answers: We all need to. There is legislation both at national (India) and at international (the world) levels which tell what governments are able to do to their citizens but, if no-one points out that their actions are violating international norms, governments can continue to violate them with impunity. As individuals, we need not only to respect the rights of others in our everyday lives but also to keep watch on our governments and on others. The protective systems are there for all of us if we use them.

- **How would you defend your rights? For example when the bus driver does not allow you to sit on the bus, because you or your family member is affected by leprosy?**

For example: if you want to defend your rights, you should point out that they have been violated. Let the other person know that you know they are not entitled to treat you in this way. Tell others about it: tell the newspaper/press, write to important people in the government or inform NGOs such as Lepra or NLR and ask for their advice and help. Make the government realise that you are not going to give up. Show them the support, from NGOs, the community and others that you draw on.

The facilitator tells the story of how TLM repealed discriminatory legislation in India. In 2016, the Ministry of Law and Justice in India repealed The Lepers Act 1898 and 29 other acts that discriminate against people affected by leprosy. These laws for example stated that leprosy affecting either spouse constitutes a ground for divorce. This goes against our human rights. It took many years of telling important people that the laws are discriminating and at the same time telling people that leprosy is a curable disease and not highly contagious. It took knowledge, perseverance and confidence to repeal the ‘Lepers Act’.

This is an example of people affected by leprosy and their supporters finding out about their rights and working together to make sure that laws are up to date with rights. These people were very resilient to keep standing up for their rights. More importantly, now that we know that the law is gone, and our rights have been accepted at the highest government level, it can help us be strong and know our rights in our daily lives.

Review

The facilitator asks each person the family:

- **What did you learn about rights today?**

For example: there are rights for everyone, there are special rights for leprosy affected persons because they are disadvantaged, there is an inequality because they are not in equal footing like everyone else is, there are protective rights to compensate this inequality such as the fundamental right of remedies against discrimination, and the disability law.

- **Is there one right you or someone in the family might have?**

For example: there are the six fundamental rights that everybody in India has. There are also the special rights for people with disabilities, and for leprosy.

- **What can you do?**

When we know our rights it makes us feel more confident as a person. It helps us to be strong and bounce back like the bamboo in a storm.

Resources used:

4. Access online to Disability ID homepage
<http://www.swavlambancard.gov.in/pwd/application>
5. Access to other portals/laws for people affected EDPAL (Eliminating Discrimination of Persons Affected by Leprosy) <http://lawcommissionofindia.nic.in/reports/Report256.pdf>
6. Principles and Guidelines on eliminating discrimination against persons affected by leprosy. https://www.ohchr.org/Documents/Issues/Leprosy/PrinciplesGuidelines_EN.pdf
7. Rights in India <https://www.nios.ac.in/media/documents/SecSocSciCour/English/Lesson-16.pdf>
8. http://eprints.whiterose.ac.uk/119241/1/Toolkit%20for%20understanding%20%26%20challenging%20leprosy%20stigma_Final%20Published%20version%20Jul%202017%20V3.pdf
9. Questions and answers have been taken from
<https://www.coe.int/en/web/compass/questions-and-answers-about-human-rights>
10. <https://www.equalityhumanrights.com/en/human-rights/what-are-human-rights>

Week 7. Beliefs and faith help us to bounce back (from difficulties like discrimination)

What to bring:

- For the Introduction and Review, bring a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- For Activity One Case study: you will need to read the case study ('a father with leprosy', below) and think about the sort of answers you might get to these questions
- The other Activities are question-and-answer discussions. You don't need any resources but practice the questions by yourself first, and think about the sorts of answers you might expect.

Aims: (What do we want people to learn?)

- We want to explain to families that many people focus on God or a higher power in difficult times and it helps in dealing with difficulties
- We want to emphasise that faith/beliefs can be very constructive for dealing with discrimination and exclusion.
- We want to confirm that many people find their belief in God gives them strength, the ability to accept things, and to cope with difficulties
- We also want to let people know that some aspects of some religions can also be negative, forcing people to accept discrimination, stigma and disadvantage.

Evidence: (Why is it important to address this?)

- Many people facing discrimination draw a sense of purpose and self-worth from their beliefs. Often these people are more resilient than others.¹
- Faith/beliefs can also help us to deal with our emotions related to discrimination and exclusion.²
- Faith/beliefs can help individuals to deal with negative life situations. Faith can provide a sense of control and an understanding of stressful situations, contributing to a positive sense of self.^{1,2}

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. An important part is the leaves of the bamboo that are strong. Our faith and beliefs are like the leaves that keep the bamboo alive. We need strong beliefs to be resilient and bounce back like the bamboo. We will talk about these beliefs this week.

The facilitator explains that this week the family is going to talk about faith and beliefs.

- We will hear about how important these are to resilience.
- We will hear about some examples of how people have become more resilient because of their faith.
- We will talk about emphasising the positive aspects of faith and beliefs
- We will discuss how you can strengthen your own beliefs and faith and how it will help you to bounce back from difficult problems.

Main messages:

- Many people have religious or spiritual beliefs, but did you know your beliefs can also be an important part of being resilient and bouncing back?
- Faith and beliefs can help us think about important things and help us get a bigger sense of who we are, and what we are capable of doing.
- In the face of discrimination and exclusion, a reliance on God can give people a sense of self-worth, regardless of what others are saying.
- Faith practices like prayer, contemplation, meditation, sacred music, etc. can help us with our emotions, but they also help our mind and our resilience.
- Many people find their belief in God gives them strength, the ability to accept things, and to cope with difficulties

Activity 1 - Case study: A father with leprosy**The facilitator reads this story to everyone**

Sunil is a rice farmer who was diagnosed with leprosy when he was 36 years old. Because Sunil was diagnosed late, he already had some visible signs of leprosy and a lot of pain. He had undergone surgery to help him walk better.

After surgery he had to use a wheelchair and became very sad. He did not want to talk to anyone or go out or do anything. After a long time, he decided he had to look to God to help him with his problems. He prayed to God asking for help with his problems.

Later he also told his family members that he was very sad, and they all agreed to pray. One day he heard his young son (5 years old) praying that he would get better and walk again.

This encouraged him a lot. He felt much less sad. He decided to do all he could. He went to rehabilitation and he did all the exercises. Eventually his feet recovered from the surgery, and now he walks quite well and he says that God and his son helped him get better.

Facilitator asks:

- What do you think of this story? (Go around the room asking each person what they think about it).
- Do you think the father's beliefs and actions helped him to be more resilient?
- Do you think telling his family was a good thing to do?

Key messages:

- Sometimes people talk to others who have faith, or they talk to a religious leader. This can strengthen them.
- Most religions bring people together, to talk together, to pray together, to worship together.
- Our beliefs help us to meet people and talk about our lives with them. This is an important part of resilience.
- Religion might also give a sense of belonging to a caring group. That is important.

Activity 2

The facilitator asks:

- What ways do your beliefs and your religion bring people together?
Example of possible answers: we pray together, we attend (and/or celebrate) festivals.
- Are there people you could talk to, or things you could do, to build your relationships with others in your religion? (If not: Are there people you talk to, or people you do things with in your religion?)
Example of possible answers: We could plan to go together to the festival.

The facilitator asks:

- Do you know people who use religion to discriminate against people affected by leprosy?
(*In case rephrasing is needed: do they say negative things about persons affected by leprosy in the name of religion?*)
Example of possible answers: Yes
- Can you give examples?
Example of possible answers: leprosy is a curse of God or a because of karma.
- What do you think of that?
Example of possible answers: There is nothing wrong with leprosy affected persons, because they are taking treatment, they cause no harm to anyone. Persons affected by leprosy did not choose to get leprosy, they got the disease like you can get any disease (e.g. the common cold). Discrimination in religion is sometimes linked to the belief that leprosy can kill people and that it is very contagious – this is not the case, leprosy can be treated with medication, is no longer contagious when you take or have completed taking medication and you can completely cure from the disease
- Have you heard people blame themselves for problems, thinking that their religion says they are bad? What do you think of that?
Example of possible answers: Yes, they think they have committed a sin and leprosy is a punishment from God.
- Do you know any examples of positive stories about leprosy and persons affected by leprosy in (your) religion?
Example of possible answers:
 - In Christianity: On his way to Jerusalem, Jesus encountered ten persons affected by leprosy. He healed them by touching them. Jesus attributed the healing to the faith of the beneficiaries. This is one of the miracles of Jesus reported in the Gospels.
 - In Buddhism, illness is not seen as a fixed, unchanging phenomenon, but simply as an expression of life.
 - Islam: Some traditions tell of Muhammad bestowing great responsibility on one his fellow Muslim who is affected by leprosy and even sharing a meal with a person affected.

Keys messages:

- But for some people, their beliefs make them afraid, anxious or stressed. That is not helpful.

- *Some people's beliefs may make them discriminate more against people affected by leprosy.*
- *Sometimes beliefs cause people to accept negative things and discrimination, so they become more disadvantaged and less resilient. That is also unhelpful.*
- *Some people think that leprosy is caused by their sin or the sin of others, and they blame themselves, but this is not true, leprosy is caused by bacteria.*

Review

The facilitator reminds people that faith and beliefs are an important part of resilience.

- Ask the family to think share any ideas they have had about becoming more resilient through their beliefs/faith. (Help the family to discuss these by saying things like “Tell me some more about that”)
- Ask the family how they might strengthen their own beliefs or faith practices, and how it will help you to bounce back from difficult problems. (Help the family to discuss these by saying things like “Please explain some more?”)
- Ask the family whether they could use prayer and meditation to help them become more resilient. (Help the family to discuss these by saying things like “Can you give me some examples?”)

Remind people of the main diagram of our project. Show the family, the diagram of this project (Being strong and bouncing back like the bamboo in a storm).

- Remind them that faith and beliefs are like the leaves of the bamboo. We need these beliefs if we are to be resilient and bounce back like the bamboo.

Resources used:

1. Sivilli, T. I., & Pace, T. W. (2014). The Human Dimensions of Resilience: A Theory of Contemplative Practices. *Garrison Institute*. New York
2. Smith, B. W., Ortiz, J. A., Wiggins, K. T., Bernard, J. F., & Dalen, J. (2012). Spirituality, resilience, and positive emotions. In L. J. Miller (Ed.), *Oxford library of psychology. The Oxford handbook of psychology and spirituality* (pp. 437-454). New York, NY, US: Oxford University Press

Week 8. Strong families help us to bounce back (from difficulties like discrimination)

What to bring:

- You will have to prepare for the Introduction and Review, by bringing a copy of the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- For Activity One and Activity Four you need the story on the pages below. Please read the story and think about possible answers to the questions
- Activity Two and Activity Three are question-and-answer discussions. You don't need any resources but you will have to practice the questions by yourself first, and think about the sorts of answers you might expect.

Aims: (What do we want people to learn?)

- This whole program is based on families. Families can be a very important part of building resilience.
- We want people to realize that leprosy affects the whole family and that the whole family could be discriminated against.
- We want the whole family to know that they will be more resilient if they realise:
 - We are all in this together as a family
 - We are stronger together as a family
 - We can overcome obstacles better together as a family
- We want to help participants create a supportive environment for the whole family (especially the person affected by leprosy)

Evidence: (Why is it important to address this?)

- Good social relationships, and especially good family relationships are vital for resilience.¹
- Family relationships provide practical and emotional support in the context of discrimination. These relationships lead to greater psychological and physical well-being.^{1,2}
- People feel less stress when we have good family and social support.²
- Social and family support improves life satisfaction.^{1,3}
- Caring relationships provide social support. It is a circular, self-reinforcing movement. The better you feel, the more you share that positive feeling with others.^{1,3}

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm).

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). There are many parts to being strong like bamboo. One of the most important parts is the soil that nurtures the bamboo and keeps it alive. The family is like the soil that holds and nurtures the bamboo. We need this soil to be resilient and bounce back like the bamboo. We will talk about these family relationships this week.
- The point of this week's session is to remind people of the importance of family, in building our resilience

Key messages:

- *Discrimination against a person affected by leprosy affects the whole family.*
- *But, in the same way that individuals can be resilient and bounce back, so can families.*

- Families can adapt and become stronger after a family member is diagnosed with leprosy.
- Families can be more resilient if they are willing to work together and support each other

Activity 1

Facilitator reads the story of Bishnu

Comment that the story is an example of a family that hasn't responded well to leprosy.

There was a family in Chhattisgarh that was known to everyone in their village. The father of the family did bicycle repairs from a small shop at the front of their house. They had four children, one daughter (Bishnu) in high school, two boys in primary school and one baby still at home. Last year, Bishnu was diagnosed with leprosy, and she has recently finished her MDT treatment. Because she was diagnosed a little bit late, Bishnu doesn't feel anything on the ends of two fingers. Sometimes Bishnu drops things when she isn't concentrating, but when she does, her mother hits her and says she is trying to avoid work. Bishnu's father also gets angry at her. He says because of her some people don't come to his shop. Sometimes he doesn't even want to have his food from the same pan as Bishnu. He says it is her fault the family is poor. Last week he said she should leave school because she isn't going to be able to do anything anyway. Her brothers also tease her and say the things they hear others say about her. Bishnu is very sad and doesn't want to go out of the house anymore. Bishnu has always tried very hard at her school work and does well, she doesn't want to miss out on her school work, but lately she has lost motivation. She thinks she is the cause of her family's problems and that they would be better off without her.

Facilitator asks:

- What is Bishnu's family doing wrong?
Example of answer: they are blaming Bishnu, they are not facing the problem together.
- What did her father do wrong? What did her mother do wrong?
Example of answer: the father avoids eating with her, the mother hits her and says she is lazy.

Key messages:

- Resilience comes from how we think and what we know, but it also comes from listening to each other. Good communication in the family build resilience and understanding.
- When our communication creates blame, the family is weakened.
- When our communication is supportive of each other, it builds family resilience.
- To be a resilient family we must listen and try to really understand the experiences that other people describe.
- To be a resilient family you need to be "other-focused". Take the time to really listen to what others say. Don't be thinking about what you want to say next. Instead, really actively pay attention to what they have to say.

Activity 2

The facilitator reads Bishnu's story again.

Emphasize that this time they will suggest new things each of the people could have done to make their family stronger.

There was a family in Chhattisgarh that was known to everyone in their village. The father of the family did bicycle repairs from a small shop at the front of their house. They had four children,

one daughter (Bishnu) in high school, two boys in primary school and one baby still at home. Last year, Bishnu was diagnosed with leprosy, and she has recently finished her MDT treatment. Because she was diagnosed a little bit late, Bishnu has a contracture and she doesn't feel anything on the ends of two fingers. Sometimes Bishnu drops things when she isn't concentrating, but when she does, her mother hits her and says she is trying to avoid work. Bishnu's father also gets angry at her. He says because of her some people don't come to his shop. Sometimes he doesn't even want to have his food from the same pan as Bishnu. He says it is her fault the family is poor. Last week he said she should leave school because she isn't going to be able to do anything anyway. Her brothers also tease her and say the things they hear others say about her. Bishnu is very sad and doesn't want to go out of the house anymore. Bishnu has always tried very hard at her school work and does well, she doesn't want to miss out on her school work, but lately she has lost motivation. She thinks she is the cause of her family's problems and that they would be better off without her.

The facilitator asks:

- What could Bishnu's father have done?

Example of response: he could have brought together the family and get them to face the problem together.

- What could her mother have done?

Example of response: she could have asked Bishnu what she can do to help around the house that she will do well.

- What could Bishnu and the family do now, to become more resilient?

Example of response: they could decide to always support one another, instead of accusing or blaming.

Key messages:

- *This family will be more resilient if each person realises that:*
 - *We are all "in this together" as a family.*
 - *We are stronger together as a family.*
 - *We can overcome obstacles better together as a family.*
- *When people are sad (like when they are diagnosed with leprosy) they may turn away from family and family support. That makes things worse.*
- *When people get sad and withdraw from others in the family, or when family members blame each other, it weakens the family.*
- *An important way that families can be more resilient is if they try to work together.*
- *It is helpful when families see that a good way of overcoming sadness within the family is when they decide to work together to overcome the sadness*
- *It is helpful when families see that a good way of overcoming discrimination from outside the family is when they decide to work together to overcome the discrimination.*
- *The important thing is working together to solve problems.*

Activity 3

Facilitator asks a few people in the family to give ideas on: What is one way that we can show others in our family that we are really listening to them?

For example: when you ask someone how you can help him/her, try to do what this person has suggested. When someone says s/he is not feeling well, try to make them feel better and ask again at a later time, to see how things are going. Make time to listen to someone.

Key messages:

- Resilience comes from taking time and building relationships. When we have strong relationships in the family we are all stronger.
- To be a resilient family we need to be “generous” with our time and attention.
- When we are generous with our time, it builds trust and makes everyone feel more positive and makes the whole family more resilient.

Activity 4

The facilitator asks: What is one thing each of us could do this week to focus on and build up other family members' strengths and abilities.

Suggestion: They might decide to tell someone one thing they like about him/her (the way to prepare tea, the way they organize the house, etc.) Ask suggestions from a few family members. Give them time to think.

Ask the following question: What could this family do in the coming week to solve problems together and to be stronger together?

Suggestion: spend time together, discuss problems more, listen to each other.

Key messages:

- Resilience comes through relationships which focus on strengths and abilities especially when those relationships encourage our best efforts.
- Resilience can come from belonging to this family.
- Resilience is in us – it is something that we can strengthen in ourselves, strengthen in our families, and strengthen in our communities.

Review

- Remind people of the main diagram of our project. Show the family, the diagram of this project (being strong and bouncing back like the bamboo in a storm).
- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). Our important family relationships are like the strong soil around the bamboo. We need these relationships if we are to be resilient and bounce back like the bamboo.

Resources used:

1. Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, 42(1), 1-18.
2. Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152-169.
3. Shih, M. (2004). Positive stigma: Examining resilience and empowerment in overcoming stigma. *The ANNALS of the American Academy of Political and Social Science*, 591(1), 175-185.

Week 9. Strong relationships outside the family help us to bounce back (from difficulties like discrimination)

What to bring:

- The main diagram of our project (being strong and bouncing back like the bamboo in a storm).
- For this week all of the activities are question-and-answer discussions. You don't need any resources but you will need to practice the questions by yourself first, and think about the sorts of answers you will give as examples and the sorts of answers you might expect from the family members.

Aims: (What do we want people to learn?)

- We want people to know that having good social relationships is vital for resilience.
- We want to remind people that good social relationships help us to bounce back from difficult problems.
- We want to emphasise that social relationships are very important for people as well as families affected by leprosy.
- We want them to realise that good social relationships lead to greater psychological and physical well-being.
- We want to explain that there are things each person can do to build social relationships and resilience.

Evidence: (Why is it important to address this?)

- Having good social relationships is vital for resilience, it leads to greater psychological and physical well-being.^{1,2}
- People feel less stress when they have social support, and this bolsters their resilience.¹
- Social support improves life satisfaction and relieves stress.³
- Caring relationships provide social support. It is a circular, self-reinforcing movement. The better you feel, and the more you share that positive feeling with others.^{1,3,4}

Introduction

Show the main diagram of our project (being strong and bouncing back like the bamboo in a storm)

- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). Our relationships with people are important like the strong soil around the bamboo. We need this soil to be resilient and bounce back like the bamboo. We will talk about these relationships this week.

Facilitator explains:

- Today we will discuss their experiences relating with people outside the family.
- We will ask questions and talk about ways we can be more resilient in our relationships outside the family.
- We will think of ways to reach out to others for help when we are in trouble.

Activity 1

The facilitator explains that one of the big problems when we face discrimination and big problems is that we want to avoid people. We close ourselves off and we don't seek the help we need.

- **Ask the family: Have you ever felt like you wanted to avoid people?**

Example of response: Yes, no, not sure. Allow time for the participants to respond however they want.

- **What did that feel like?**

For example: it can make you feel sad, not understood and lonely, like you have no friends.

- **Ask the family: What happens to people when they close themselves off from others?**

Ask each person for suggestions. When they offer a suggestion, say “Thank you”, repeat it and then ask for the next suggestion. At the end of all the suggestions, summarise them and repeat them back to the family. Example of answers: they feel alone and sad, they may stay inside the house, they do not connect with other people, they do not go out to do nice things that make them feel good, they do not talk about what bothers them.

- **Ask the family: What is usually the outcome when people close themselves off from others?**

Examples of possible answers: breaks relationships, lose social support, become depressed, withdraw more from offers, relationships disappear.

Key messages:

- *If we want to be resilient, we have to do the opposite of closing ourselves off.*
- *We all need supportive relationships to do well and to adapt to difficult circumstances like leprosy.*
- *We know from research that resilient people have at least one friend and a network of supportive people*

Activity 2

Often when we are in trouble, we look to our social networks for help (for emotional support or simply a helping hand).

- **Ask the family members: Think back to a situation in which they got help from others in their village or from friends. How did that feel?**

Facilitator provides an example from his/her own life experience of when he got help from another. Explains situation, explains help, explains how he/she felt, explains outcome.

- **Ask the family members: What happens (what are the outcomes) when we connect with others?**

Example responses might include “problems can be solved” “work together” “feel supported”

Key messages:

- *Having friends you can talk to and share your concerns with, and maybe asking them to help you, is important.*
- *Our local villages and communities can also help us be more resilient. We can rely on peers and elders for emotional support. This is very important.*
- *When we have strong relationships with others in our community, we can get their advice and their practical support. This is especially important when we face problems.*
- *Resilience comes from being involved in our community.*

Activity 3

- **Ask the family: Who are some people in your village whom you trust, who you can build stronger connections with?**

Example of responses might include next door neighbour. Take time and wait for them to think about this question.

- **Ask the family: What is the best way to build social connections in this community?**

Suggestions: Ask one or two people for suggestions. When they offer a suggestion, say "Thank you", repeat it and then ask for the next suggestion. At the end of all the suggestions, summarise them and repeat them back to the family.

- **Ask the family members to think of ways they can get support from others in their community to help them in the area of discrimination.**

Suggestion if they do not know how to respond: "how they could use social support to help them deal with stigma and discrimination?"

- **Ask them to think of ways they can give support to others in their community.**

Example of response: Watch their children if they need to go out.

- **Ask them: Who are people in this community who might need more support?**

Suggestion: Take time for people to respond.

Key messages:

- Resilience comes from having healthy relationships with others outside our families.
- But resilience also comes from helping others and being a strong support to others in our community.
- When we help others in meaningful ways (emotionally and practically), we are also helping in their resilience. We are contributing to the resilience of our community.
- Helping others, talking to others, supporting others and being an emotional support builds resilience.

Review

- Remind people that this session was about social relationships, which are very important for all people, including people and families affected by leprosy.
- Remind people of the main diagram of our project and show them.
- Explain that we want people to be strong and bounce back like the bamboo in a storm (not like the tree that breaks in a storm). The strong soil around the bamboo is like the relationships we need to be resilient and bounce back like the bamboo.
- Remind people of family gathering in week 10 (time/location). Explain that we would like them to tell others about the most important thing they learned in this project. We would like them to do that through a small song or a small "role play" or just telling the other families like them, who will be there.

Resources used:

1. Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152-169.

2. Zautra, A. J., Arewasikporn, A., & Davis, M. C. (2010). Resilience: Promoting Well-Being Through Recovery, Sustainability, and Growth. *Research in Human Development*, 7(3), 221-238.
3. Yang, C., Xia, M., Han, M., & Liang, Y. (2018). Social Support and Resilience as Mediators Between Stress and Life Satisfaction Among People With Substance Use Disorder in China. *Frontiers in Psychiatry*, 9(436).
4. Garnezy N. (1985). Resiliency and vulnerability to adverse developmental outcomes associated with poverty. *American Behavioral Scientist*, 34: 416–30.

Week 10. Having fun and bouncing back with other families

What to bring:

- The following is important to arrange before the gathering:
 - Prepare the facility where the gathering will take place.
 - Inform participants where the gathering will take place.
 - Make the arrangements for food and drinks.
 - Make arrangements for transportation of families to the venue.
- For the Introduction, bring the testimonial videos of Rachna and Amal and a screen to display the videos.
- For Activity One, you need music and chairs to play musical chairs (volume should be adequate).
- For the Review, bring a printed picture of each of the families.

Aims: (What do we want people to learn?)

- We want to bring people together to discuss the experiences they've had with the resilience intervention.
- We want to get new insights and perspectives from the experiences of the other families.
- We want to expand friendships and support networks of the families and reduce isolation by getting in touch with families who face the same issues.

Evidence: (Why is it important to address this?)

- Of the many functions served by families, social support is among the most important.
- Social support provides people with practical help and can help people cope better with stress.¹
- A sense of connection to a group of others is a key support component for physical health also.²
- Friendship quality is an important predictor of happiness.³

Introduction

All family members are given tea. After that, **one of the facilitators welcomes all families to the social gathering and shares how s/he experienced the resilience intervention/weeks/sessions.**

The facilitator explains that the purpose of the gathering is as follows:

- To bring the different families together to discuss the experiences they've had with the resilience intervention.
- To hear and learn from the experiences of the other families and also share their own experiences.
- To expand friendships!

One of the facilitators explains the programme of the day:

- The day will start with an opening statement.
- After that, the families will watch two testimonial videos together.
- The families will play musical chairs.
- When there is a winner of musical chairs, the families will discuss the past months (the intervention).
- Lunch will be served at the end.

Another person (preferably Preetha in Orissa and Mohammed Ilyas in Hyderabad) are asked to give a brief **opening statement**.

The testimonial videos of Amal and Rachna are shown. After that, the facilitator makes a brief wrap up referring to the bamboo:

- In the case of Rachna, the difficulties she had to overcome were her disease and the divorce that followed her diagnosis. Rachna had strength from her family members, her father and mother who supported her during the difficult times. She also got strength from correct knowledge about the disease which gave her strength to overcome and stand tall and strong like a bamboo.
- In the case of Amal, the hardship was the rejection by his family and friends in his village. Amal got support outside the family through the medical staff at the hospital and the teachers at the boarding school he attended. They helped him to be resilient and overcome the difficulties he faced.

The facilitators encourage participants to talk to and get to know the other families.

Activity 1

This activity will take approximately 30 minutes.

The first activity is a warm-up activity. **Musical chairs is played with all families.** One of the facilitators controls the music, other facilitators take away a chair (one every time the music starts playing again). The winner of musical chairs is applauded.

Activity 2

The facilitators asks all families to give their description or performance. This can be a dance, story, song, puppet show or simply a short statement about what they've learned.

After all families have done their performance, the following is discussed:

- **What have you learned the past few weeks? Do you have examples?**
- **Have you already used anything you've learned? What? How?**
- **Do you have any suggestions for how to help other families facing discrimination?**
- **Do you have suggestions to improve the meetings you've had over the past few weeks? Was there anything that wasn't relevant?**

The facilitators encourage participants to talk to the other families.

Review

- The families are thanked and given a printed picture of their family.
- Lunch is served.
- **The facilitators explain that they will visit the families one more time to again administer the questionnaires (a date has already been agreed on in week/session 9).**

Resources used:

1. Miller, T. A., & DiMatteo, M. R. (2013). Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes, metabolic syndrome and obesity: targets and therapy*, 6, 421.
2. Hale, C. J., Hannum, J. W., & Espelage, D. L. (2005). Social support and physical health: The importance of belonging. *Journal of American College Health*, 53(6), 276-284.

3. Demir, M., & Özdemir, M. (2010). Friendship, Need Satisfaction and Happiness. *Journal of Happiness Studies*, 11(2), 243-259.