

TOOLKIT FOR

UNDERSTANDING AND CHALLENGING LEPROSY-RELATED STIGMA

FOR CIVIL SOCIETY ORGANISATIONS
IN INDIA



European Union



The Leprosy
Mission
England and Wales



The Leprosy Mission
Trust India

Leading inclusion, dignity



UNIVERSITY OF LEEDS



UNIVERSITY OF LEEDS

Publication Year: 2017

Authors & Contributors: Mr. Anish Joy, Pr Chigulla Elisha, Dr. Ebenso Bassey, Mr. Gareth Shrubsole, Mr. Harsha Gudasalamani, Dr. M. S. Raju, Mr. MathanRaj David, Dr. Mahua Das, Ms. Nikita Sarah, Ms. Tina Mendis and Mr. Victor Parisipogula.

Disclaimer:

This Toolkit is the property of The Leprosy Mission. It is a guide for members of Civil Society Organizations (CSOs) operational at community level in India. The Toolkit builds the capacity of CSOs in promoting inclusion of people affected by leprosy and other disabilities. CSOs and like-minded organizations are encouraged to use this toolkit to work with field workers and local Governments to dialogue with communities for challenging and eliminating stigma and discrimination against people affected by leprosy/disabilities.

Use and/or Reproduction of the contents of this toolkit is permitted provided The Leprosy Mission is duly acknowledged whenever the toolkit is used.

This publication has been produced with the assistance of the European Union. The contents of this publication are the sole responsibility of The Leprosy Mission and can in no way be taken to reflect the views of the European Union.

Citation and Acknowledgments

Acknowledgements

The work leading to this output was funded by the European Union's "Capacity Development and Promotion of Diversity for Inclusive, Sustainable Growth in India" grant: reference number Europe Aid DCI-NSAPVD/2015/368-847.

The CREATE project conducted an extensive literature review of existing toolkits in the fields of health-related stigma, disability, gender-based violence, and international development, the findings of which informed the development of a toolkit for use by Civil Society Organizations (CSOs) for challenging and reducing leprosy-related stigma. This toolkit was pilot-tested with field workers from Andhra Pradesh and field workers & CSO members from Uttar Pradesh.

Through their active participation, field workers and CSOs in the two workshops where the toolkit was tested, gave the toolkit the benefit of their ideas and experiences and helped keep it focused on the practical needs of and challenges faced by people affected by leprosy.

CREATE

CREATE is a three-year project (2016-18) implemented under the European Union's "Capacity Development and Promotion of Diversity for Inclusive, Sustainable Growth in India" Initiative. The project aims to enhance and develop the capacity of Civil Society Organizations in 18 districts across four Indian states (of Uttar Pradesh, Chhattisgarh, Andhra Pradesh and Tamil Nadu), to function as change agents for those affected by leprosy and other disabilities.

CREATE involves three partners:

1. Brighter Future Development Trust
2. The Leprosy Mission Trust India
3. The Leprosy Mission England and Wales

Table of contents

Citation and Acknowledgments	i
Table of Contents.....	ii
Glossary.....	iv
Acronyms.....	vii
Introduction.....	1
How and why this toolkit was developed.....	1
What is a toolkit?	2
Purpose of the stigma toolkit	2
Who is the toolkit for?	3
Why focus on stigma and discrimination?	3
Guiding principles of toolkit	3
How the toolkit is to be used.....	4
Organization of the toolkit.....	5
Outline of a workshop	6
Module 1: What is leprosy?	8
Exercise 1.1: What we think about leprosy (35 minutes).....	9
Exercise 1.2: Ways in which leprosy may be spread. Risk Continuum (35 minutes).....	10
Exercise 1.3: Distinguishing Facts and Myths about leprosy. (25 Minutes).....	11
Exercise 1.4: Promoting fuller understanding and confirming lessons learned (20 Minutes).....	12
Module 2: What is stigma?	14
Exercise 2.1: Naming stigma in different contexts through pictures (1 hr).....	15
Exercise 2.2: Portraying stigmatizing attitudes in government establishments (1 hr).....	16
Module 3: How we stigmatize others.....	19
Exercise 3.1: We are all in the same boat (15 mins).....	19
Exercise 3.2: Things people say about other different groups of people. (1 Hour 30 mins).....	21
Module 4: How it feels to be stigmatized.....	24
Exercise 4.1: Personal testimonies of being stigmatized—not linked to leprosy (1hour).....	25
Exercise 4.2: How it feels to be stigmatized because of leprosy(1 Hour).....	26
Module 5: Understanding Human Rights.....	28
Exercise 5.1: Assessing baseline understanding of rights (40 minutes).....	29

Exercise 5. 2: Understanding specific rights and responsibilities of people affected by leprosy (40 minutes).....30

Exercise 5.3: Understanding Human Rights Instruments that safeguard and promote the rights of people affected by leprosy and its use in addressing violation of Human Rights (70 minutes+ extra 40 minutes if movie “Unwanted” is shown)31

Module 6: Action towards inclusion of people affected by leprosy35

Exercise 6. 1: Lessons learned from Modules 1-5 (30 mins)36

Exercise 6.2: Disseminating lessons learned using social communication and advocacy 37

Exercise 6.3: A Community Free of Leprosy Stigma and Discrimination (45 mins)38

Exercise 6.4: Action planning through CSO case study (45 minutes)38

Essential Steps in Action Planning for a Stigma-free Community41

Appendix 1: Questionnaires for assessing stigma42

 A. The P-Scale showing domains of life represented42

 B. SARI Stigma Scale45

Appendix 2: Washington Group Questions on Disability47

Appendix 3: Facts about Leprosy for advocacy and awareness in Communities48

Appendix 4: Guidance on impact of leprosy on psychological and emotional wellbeing51

Appendix 5: Human Rights, Laws and Entitlements of People Affected by Leprosy56

 Appendix 5(A): Human Rights56

 Appendix 5(B): Rights guaranteed under the Indian Constitution.....58

 Appendix 5(C): United Nations Convention on the Rights of Persons with Disabilities and Rights of People with Disabilities (RPD Bill)59

 Appendix 5(D): United Nations’ Resolution No. A/HRC/15/3061

 Appendix 5(E): Report No. 256 on ‘Eliminating Discrimination against Persons Affected by Leprosy’63

Appendix 6: Tips on working with the media to publicise leprosy-related stories66

Appendix 7: Guidance for accessing government welfare schemes in India.....67

Appendix 8: Welfare Schemes available across Four States that participated in CREATE Project..74

Appendix 9: Picture cards used in modules80

 A. Signs and symptoms of leprosy, Diagnosis and treatment of leprosy.....80

 B. Stigma Picture cards or illustrations (for Module 1 , 2 , 3 & 6)84

Appendix 10: Toolkits consulted for designing the CREATE toolkit110

References.....111

Glossary

This glossary lists definitions of key terms used in this toolkit to ensure a common understanding of key concepts among CREATE partners for addressing stigma in India.

Key terms:	
Accessibility	The degree to which an environment, service or product can be reached, understood or approached by as many people as possible, in particular people with disabilities. This includes access to buildings, transportation and formats of communication(WHO 2011).
Advocacy	This means getting support from another person or group of people to help you express your views and wishes, and to help make sure your voice is heard. Someone who helps you in this way is called your advocate (Mind.org.UK 2013). Advocacy also represents actions that involve supporting, pleading for, recommending and highlighting issues in order to change “what is” into “what should be”, in the belief that “what should be” will lead to a more decent and just society (Wikipedia 2016).
Anxiety	Anxiety means fear, nervousness and worry that is more severe and longer lasting than typical everyday worries, and interferes with someone’s normal work and relationships.
Comprehensive accessibility	Ensuring that barriers to participation in community processes, and to justice, services and facilities are identified and addressed. These include physical barriers, communication barriers, attitudes and policy barriers.
Counselling	Counselling is a two-way process in which a counsellor or psychologist helps people to expand their view of life; enlarging their range of coping resources and enabling them to make choices to bring about change in themselves, in their situation and environment without harmful consequences to the self or to others (Yeo 1993).
Depression	Depression is an unusually sad mood that does not go away.
Disability	Disability is a social process that results from the interaction between persons with impairments and the attitudinal and environmental barriers that prevents their full and effective participation in society on an equal basis with others (United-Nations 2007).
Disability Inclusion	Disability inclusion is part of a wider movement for inclusive development that strives for active participation and representation of all people regardless of age, gender, disability, ethnicity, race, class, religion, sexuality or any other characteristic(Al Ju’beh 2015).
Disability-inclusive development	Disability-inclusive development is part of a social justice movement that challenges unjust systems and exclusive policies, relations and practice (Al Ju’beh 2015).
Discrimination	Discrimination is any form of action, inaction, document or behaviour, which results in a differential treatment of an individual or a specified group, minority or community that is negative in both or either its consequence and impact.

Empowerment	A process by which people or groups who are powerless become aware of the power dynamics at work, in their life context, and take steps to develop the skills and capacity for gaining control over their lives, exercise their control without infringing on the rights of others and support the empowerment of others in the community.
Entitlement	Something that you have a right to do or have. The right to do or have something
Equality	Having access to the same opportunities in life as others to participate in community activities (regardless of age, sex, race, disability or any other characteristic).
Gender	Gender refers to social attributes and opportunities linked to being female and male and the relationships between women and men and girls and boys, as well as the relations between women and those between men. These attributes, opportunities and relationships are socially constructed and are learned through social upbringing. They are context/ time-specific and changeable.
Injustice	Refers to inequality or lack of fairness which commonly manifest in the context of employment opportunities, wages etc. Injustice is often used inter-changeably with the word discrimination, or used in the same sentence as the word discrimination.
Human rights	Refer to the rights that everyone has just by being human, irrespective of citizenship, nationality, race, ethnicity, language, gender, sexuality, or abilities. You don't have to be a member of a particular group, and nobody needs to give you your rights. Everyone is automatically entitled to enjoy the full range of human rights just because they are human (Office of the High Commissioner for Human Rights). Every human being has rights by birth.
Mental health	Mental health is not just the absence of mental disorder. It is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community (WHO 2014).
Participation of people with disabilities	Participation is a process that aims to empower people with disabilities by involving/including them equally as non-disabled peers in every aspect of life including in political and social decision-making processes related to policymaking, planning and administration (WHO 2011).
People or persons affected by leprosy	This denotes anyone who has been diagnosed to have leprosy, treated with multi-drug therapy (MDT), and/or released from MDT but is still living with physical, psychological and/or social consequences of the disease. This also includes members of household and communities of those who have been diagnosed, treated and released from MDT.
Stigma	Stigma is a negative response to human differences. These human differences may be obvious visible signs or differences in behaviour, or they may be more subtle. If such negative responses are related to a health condition, we call this response 'health-related stigma' (ILEP 2011, Stigma Guide 1).

Toolkit	A toolkit is a document developed to stimulate the process of dialogue at the community level, to help the community to begin to understand certain issues/concepts at a very basic level e.g. stigma. The ultimate aim of stimulating community dialogue is to bring about positive change in attitude and practices that exist in the social relations of men and women in society (Heng <i>et al.</i> 2013; Oxfam 2006).
Well-being	<p>Well-being is defined as ‘a positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity’ (Department of Health 2010).</p> <p>Well-being requires that basic needs are met, and inner well-being is about individuals having a sense of purpose, and feeling they can achieve important personal goals and participate in society.</p>

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
BFDT	Brighter Future Development Trust
CBO	Community Based Organisation
CREATE project	Civil Society Organizations for Resource mobilisation, Empowerment, Advocacy, Training & Employment (CREATE) project
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
DID	Disability-Inclusive Development
DPO	Disabled People's Organisation
EU	European Union
EVAW	Elimination of violence against women
GOI	Government of India
HIV	Human Immunodeficiency Virus
HIV-AIDS	Human Immunodeficiency Virus-Acquired Immunodeficiency Syndrome
MDT	Multi Drug Therapy
NGO	Non-Governmental Organization
NTD	Neglected Tropical Disease
PHC	Primary Health Centre
PRI	Panchayati Raj Institution
PWD	Persons/people with disability
SHG	Self Help Group
TLMEW	The Leprosy Mission England and Wales
TLMTI	The Leprosy Mission Trust India
TB	Tuberculosis

Introduction

How and why this toolkit was developed

The Leprosy Mission Trust India (TLMTI) is the largest development organization in India that works with people affected by leprosy and other Neglected Tropical Diseases (NTDs); People with Disabilities (PwDs) and other marginalized groups. Areas of expertise of TLMTI include:

- All aspects of leprosy care including specialized leprosy referral services
- Primary-level promotive and preventive healthcare through community outreach
- Secondary-level healthcare (dermatology, ophthalmology, general medicine, general surgery, and obstetrics and gynaecology etc.)
- Institutional- and community-based disability management
- Institutional- and community-based rehabilitation and livelihood skills training
- Community-based inclusive development
- Advocacy and communication
- Research including laboratory-based, clinical and social science research
- Programme management, monitoring and evaluation
- Audit and risk management.

Through its community-based inclusive development and advocacy programmes, TLMTI uses a rights-based approach to mainstream people affected by leprosy into the larger social, cultural and political life. TLMTI also creates mass awareness focused on addressing misconceptions and harmful cultural practices about leprosy, using strategic communication and platforms of engagement to highlight the multiple facets of leprosy. The aim of awareness campaigns is to ensure behaviour change and to stimulate positive social action among all stakeholders for counteracting structural and systemic inequalities and building an inclusive society. Alongside the awareness drive, groups of people affected by leprosy are formed, educated on their rights and entitlements and linked with other agencies and bodies that address issues of marginalization so that they can be empowered. TLMTI also engages with government departments and representatives to develop policies and enabling legislative environment that create and sustain social transformation.

The CREATE project (Civil society organizations for Resource mobilization, Empowerment, Advocacy, Training and Employment) funded jointly by the European Union (EU) and The Leprosy Mission England & Wales (TLMEW), and implemented jointly by TLMTI and Brighter Future Development Trust (BFDT) is an initiative that aims to develop the capacity of civil society organizations (CSOs), to promote disability-inclusive development and socio-economic empowerment. Through the CREATE project, TLMTI and Brighter Future are:

- Building the capacity of CSOs of people affected by leprosy and/or disability to become independent change agents, challenging injustice and engaging in community development.
- Sensitizing Panchayati Raj Institutions (PRIs), Self Help Groups (SHGs), Disabled Peoples' Organisations (DPOs) & Non-Governmental Organisations (NGOs) to ensure inclusion of people affected by leprosy and/or disability, and facilitate collaborative advocacy on issues of equality and injustice.
- Building the capacity of CSOs to raise awareness of employers and support the inclusion of people affected by leprosy and disability in the workplace; documenting and sharing learning with public, private and NGO sectors.

Through the CREATE project, TLMTI and Brighter Future conducted operational research in Andhra Pradesh, Chhattisgarh, Tamil Nadu and Uttar Pradesh to generate evidence for the project's advocacy efforts against stigma and discrimination. The research was supported by researchers from the University of Leeds, UK who are experts in stigma research. Data collection methods used during the research included: i) quantitative surveys of levels of participation restriction of people affected by leprosy; ii) semi-structured interviews with key informants and family members; and iii) case studies of injustices and discrimination faced by people affected by leprosy. Findings from the operational research were used to inform development of this *"Toolkit"*, which will be a practical resource for understanding and challenging leprosy-related stigma and discrimination in India.

What is a toolkit?

For the CREATE project, a toolkit is a document developed to stimulate the process of dialogue at the community level, to help the community to understand certain issues or concepts pertinent to them, in this case, leprosy and stigma.

Purpose of the stigma toolkit

The overall goal of any anti-stigma work is to bring about positive changes in attitude and practices that exist in social relations of men and women in society. The change that is required is not something that can happen overnight—it is a gradual process. Specific objectives of the leprosy-related stigma toolkit are:

1. Help participants see that stigma exists in various spheres of life (family, education, employment, religion etc.), that stigma hurts people affected by leprosy and can fuel the spread of leprosy and obstruct efforts to help those affected by it.
2. Provide space in which participants can discuss their own feelings and fears, and the values that underlie stigma and discrimination. Help them critically look at their own attitudes.
3. Improve participants' knowledge about leprosy to overcome fears and misconceptions about transmission and spread of leprosy. An increased understanding and awareness will allow them to serve as community hubs of information on leprosy, model more supportive behaviours, and advocate for reduction of leprosy related stigma and discrimination.
4. Enable participants to acknowledge the barriers and injustices faced by people affected by leprosy, and to question and challenge the view that injustices and discrimination are acceptable norms.
5. Provide opportunities for people to talk about how they can help reduce stigma and develop practical strategies for challenging stigma and discrimination.
6. Provide practical guidance on the rights and entitlements of people affected by leprosy and how they can access them. Such guidance will include sign posting people to where to go and who to contact to obtain further support and information about issues related to employment, social entitlements, legal advice, mental health etc.

The above objectives can be achieved in an environment where people do not feel rushed or pushed to change. The toolkit attempts to start a process of dialogue at the community level, to help field workers and CSOs understand concepts of stigma and discrimination. As it is to be used at the community level, the toolkit avoids a confrontational approach and sees field workers, CSOs and community members as partners working together to bring about change.

Who is the toolkit for?

The toolkit will be used primarily by members of CSOs at community level in India. By CSOs, we refer to Self Help Groups (SHGs), Disabled Peoples' Organisations (DPOs) & non-governmental organizations (NGOs) working at grassroots to bring about inclusion of people affected by leprosy and other disabilities. CSOs are encouraged to work with field workers and local governments in using the toolkit to dialogue with communities for challenging and eliminating stigma and discrimination against people affected by leprosy/disabilities.

Why focus on stigma and discrimination?

Fear of being stigmatized because of leprosy can keep people from seeking diagnosis for leprosy, disclosing that they have leprosy to their contacts, and accessing treatment. The disease thus continues to spread as people who do not know they have leprosy (or are afraid to discuss their status) infect their contacts. In addition, people who avoid diagnosis and/or treatment due to fear of stigmatization increase their own risk of developing life-changing disabilities with every month of delay. Stigma and discrimination must thus be addressed so that people living with leprosy feel safe enough to be tested, share their results with close contacts, and access EARLY treatment, care and support.

Key findings of the operational research conducted between July and October 2016 among 365 people affected by leprosy in the states of Andhra Pradesh, Chhattisgarh, Tamil Nadu and Uttar Pradesh showed that almost $\frac{2}{3}$ of those surveyed faced moderate to extreme level of participation restriction. Specifically, 231 of 365 (or 63.3%) of the people affected by leprosy surveyed were excluded from participating in various specific aspects of life, such as major festivals, family functions and community events.

Asked why such high levels of stigmatization persisted against people affected by leprosy despite several decades of leprosy control activities in India, key informants and family members interviewed for the research cited enduring traditional beliefs, myths and misconceptions as the roots of stigma in the four States. Prevailing cultural and religious beliefs held by and/or misconceptions mentioned by >50% of key informants and family members included: i) *fear of leprosy spreading from people affected by leprosy to healthy children*; ii) *the belief that people affected by leprosy should not be allowed to stay at home with family members or employed in farm labour as they can spread the disease to others*; iii) *avoidance of making friends with those affected by leprosy because they were abnormal*; and iv) *excluding people affected by leprosy from participation in religious functions because they are ritually unclean*.

The findings of this research underline the significance of developing the capacity of civil society organizations in 18 districts across Andhra Pradesh, Chhattisgarh, Tamil Nadu and Uttar Pradesh, to function as change agents for challenging and addressing stigma and discrimination against people affected by leprosy and other disabilities.

Guiding principles of toolkit:

This toolkit approaches the issue of stigma and discrimination against people affected by leprosy using the **human rights-based approach**. Field workers and CSOs can use the guiding principles of this approach to promote a socially inclusive community response to stigmatization of people affected by leprosy.

The human rights-based approach requires consideration of the rights of people affected by leprosy to be assured, free from cruel, inhuman and degrading treatment, to have their privacy respected and their right to life upheld. This approach aims to improve access to services and the quality of service that people affected by leprosy receive. It offers a useful framework for dealing with the complex and challenging issues that arise from the interplay between leprosy and experiences of stigma and discrimination, which have often combined to render people affected by leprosy invisible, powerless and silent.

Underpinning this approach is the core principle that persons affected by leprosy have rights, and society has a responsibility to work with them to ensure these rights are realised.

Principles used throughout the toolkit include:

- **Awareness** of leprosy and the negative social and personal impacts of stigma and discrimination on people affected by leprosy
- **Participation** of people affected by leprosy as essential for genuine empowerment and community change
- **Empowerment** – Ensuring that people affected by leprosy and disabilities are aware of the power dynamics at work, in their life context, and take steps to develop the skills and capacity for gaining control over their lives and making informed choices
- **Non-Discrimination and Equality**– People affected by leprosy/disabilities have the right not to be discriminated against and the right to be treated with equal dignity and respect.
- **Comprehensive accessibility** to ensure that barriers to participation in community processes, and to justice, services and facilities are identified and addressed. These include physical barriers, communication barriers, attitudes and policy barriers

How the toolkit is to be used:

The toolkit uses simple activities and pictures and is based on a participatory approach which requires active involvement of the group being trained to use the toolkit—in this case CSOs. This approach encourages participants to share their views and opinions irrespective of their age, sex or educational background. The group's active involvement helps to build trust, self-esteem and sense of responsibility. It also helps the group learn from and respect one another. To bring about change in attitudes and practice, a process of dialogue must be initiated, and the toolkit attempts to do this.

As the toolkit is developed to be suitable for members of CSOs and community members who cannot read or write, pictures and discussions are used during workshops. Role plays, group exercises and conversations are used to encourage participants to share their views and learn from each other. The target groups are CSOs and community members who may hold prejudices against people affected by leprosy. Including a representative number of people affected by leprosy in the workshops is found to be a great way for others to learn from them and to have discriminatory attitudes really challenged and transformed.

Contents of the toolkit:

The toolkit contains six modules and their accompanying exercises that can be used to help audiences understand leprosy, and discuss and challenge stigma and discrimination against people affected by leprosy at community level. The modules include: i) a step-by-step guide to help facilitators run module exercises and ii) a set of picture cards, illustrations and case studies to be used during the module exercises. The picture cards, illustrations and case studies are to be used with men and women from communities during the exercises for each module.

Ideally, a workshop should be delivered by 2 to 4 facilitators who are confident in leading participatory conversations and can guide small group discussions. The workshop could be delivered for up to 25 people.

The toolkit has been developed for India but can be adapted to other contexts to ensure that delivery, warm-up exercises, and key messages are culturally appropriate.

Organization of the toolkit:

The modules of the toolkit are organized to help participants learn in a gradual, incremental way.

Module 1: CSOs learn in succession about leprosy, its spread, treatment and its prevention.

Module 2: CSOs learn about the concept of stigma, and how stigma occurs in different settings or spheres in society.

Module 3: Participants understand how the community stigmatizes people; and attitudes and practice can be stigmatizing.

Module 4: Creates an understanding on how people affected by leprosy feel about being stigmatized.

Module 5: Participants are introduced to the subject of rights and responsibilities.

Module 6: Stimulates thinking about what CSOs and community can do to change their own attitudes and practices; and help develop an action plan for achieving a stigma-free community.

The 6 modules are followed by an extensive set of Appendices which give practical information and guidance about several important topics referred to in the modules. Facilitators should read the appendices relevant to each module before leading workshops and will find them helpful in answering questions which participants may raise. CSOs planning actions to respond to stigma in their communities will find these appendices useful resources to support these plans or guide further learning/training or partnerships on particular issues.

The toolkit is organized in this way to facilitate a gradual process of building understanding, commitment, strategies and collective action to create a stigma-free society. Each module prepares the ground for the next module. For instance, the first two modules are impersonal, introduction, learning about leprosy, analysing stigma in pictures with no personal involvement. Then the process becomes personal (modules 3 and 4), asking participants to think about, How are we all implicated as people who stigmatize? How does it feel to be

stigmatized? The first three modules use picture cards to get people talking and sharing. This creates the trust and openness necessary to do the more challenging modules in which people share feelings about being stigmatized and then work together on looking at solutions.

Note: The modules can be used selectively and flexibly to develop training programmes for different audiences, bearing in mind the importance of building learning incrementally. Ideally, the discussions and learning will move participants through the 10 steps to stopping stigma and discrimination:

1. Create a safe environment to talk about leprosy, stigma and discrimination.
2. Help participants to NAME THE PROBLEM by describing how leprosy-related stigma occurs in different contexts.
3. Help participants OWN THE PROBLEMS OF STIGMA AND DISCRIMINATION—to recognize that we are all part of these problems. Help participants reflect on their own words, attitudes and actions.
4. Help participants see the EFFECTS OF STIGMA AND DISCRIMINATION on people affected by leprosy, their families and communities— how it hurts people who are stigmatized, and indirectly hurts people who are perpetrating the stigma and discrimination.
5. Analyze the ROOT CAUSES OF STIGMA, such as fears and misunderstanding about transmission of leprosy, moralizing attitudes, and society's use of distancing to push away and exclude people affected by leprosy.
6. Address FEARS AND MISCONCEPTIONS about getting leprosy through casual contact, religious pollution etc. and build TECHNICAL KNOWLEDGE on leprosy care services (diagnosis, treatment etc.).
7. Challenge the VALUES that underlie stigma and discrimination and help participants get an insight into their own attitudes.
8. Build COMMITMENT to changing attitudes and doing something about stigma.
9. Help participants learn the attitudes and skills to SUPPORT AND CARE for people affected by leprosy, including counselling for those are stigmatized and discriminated against.
10. Develop STRATEGIES and PLANS for action against stigma and discrimination.

Outline of a workshop:

If CSOs wish to deliver the six modules in the toolkit in one go, they will need 2 full days of discussions, as indicated in the schedule that follows. However, CSOs may choose to take longer over this toolkit, for example doing one module per week or per month at their regular Community or Self-Help Group meetings, in which case the whole toolkit would take 6 meetings to deliver.

Regardless of how CSOs choose to use the modules, they should remember to also allow time before-hand to prepare and print relevant sheets and activity cards (picture cards) needed for the exercises that accompany the modules!

MODULES	OBJECTIVES	DURATIO	TIME
DAY 1			
Preambl	Introduction Introduce the workshop; set ground rules; use a warm-up activity to help participants feel comfortable (and introduce themselves if new to each other).	30 mins	08:30 – 09:00
Module 1	What is leprosy? Test existing knowledge about leprosy and stigma, to help participants understand signs and symptoms of leprosy, cause of leprosy transmission, diagnosis and treatment. Myths and misconceptions about leprosy	2hrs	09:00 – 11:00
	Tea Break	15 mins	11.00- 11.15
Module	What is Stigma? Participants understand: what is stigma as a concept; and use pictures to name leprosy stigma; explore the forms, the effects and causes of leprosy stigma; and naming different contexts in which stigma occurs including stigmatization at home, in health care setting, stigma in the workplace	2hrs	11:15 – 13:15
	Lunch Break	1hr	13:15 – 14:15
Module 3	How we Stigmatize others. We are in the same boat—Elimination games; stigma in the center; things people do or say about people affected by leprosy and other groups.	1hr 45 mins	14:15 – 16:00
	Tea Break	15 mins	16:00-16:15
Refresh	Recap of learning from Day 1	15 mins	16:15-16:30
DAY 2			
Module	How it feels to be stigmatized Participants reflect on how it feels to be stigmatized; people affected by leprosy testify about feeling stigmatized and discriminated against; participants understand the effects of stigma including psychological and emotional effects.	2hrs	08:45 – 10:45
	Tea Break	15 mins	10.45 – 11.00
Module 5	Understanding Human Rights Participants understand human rights and have an appreciation for rights of the individual; value the fact that people affected by leprosy and disabilities have rights and responsibilities. Help people affected by leprosy realize their rights	2hrs 30 mins	11:00 – 13:30
	Lunch Break	45 mins	13:30 – 14:15
Module 6	Action Towards Inclusion Participants are aware of barriers and inclusive practices; challenge values and ideas that discriminate against people affected by leprosy and help communities to be inclusive of people affected by leprosy.	2hrs 30 mins (including short break)	14:15 – 16:45
Workshop evaluation	Post-workshop evaluation Assess how participants felt about the training/discussions, what they learnt, how they will use the toolkit and any suggestions for improvements.	45 mins	16:45 – 17:30

Module 1: What is leprosy?

This module explores knowledge, attitude and perceptions about leprosy, so that participants have the right information about leprosy and understand the fears and misconceptions about leprosy which need to be overcome.

Module Objectives: This module will enable participants to

1. Identify and understand common beliefs about leprosy in their communities.
2. Learn more basic facts about leprosy and separate truths from myths to reduce fear and misunderstanding of leprosy.

No.	Exercise	Brief description of exercise	Time
1.1	What we think about leprosy.	Brainstorming around 7 questions to create a baseline of understanding of leprosy within the group.	35 minutes
1.2	Ways in which leprosy may be spread (risk continuum)	Common beliefs about leprosy transmission are explored and participants learn about the real risks behind them.	35 minutes
1.3	Distinguishing facts and myths about leprosy	Participants review the beliefs they have already listed and collectively determine which they think are true or false, which is then confirmed or corrected by the facilitator.	25 minutes
1.4	Promoting fuller understanding and confirming the lessons learned	Participants confirm what they have learned by distinguishing TRUE and FALSE statements and matching them to the 7 questions and the sheet of common myths.	25 minutes

Module Outputs:

At the end of this module, participants will have produced 8 flipchart sheets, 7 of which detail the beliefs and understandings about leprosy which are prevalent amongst the group and their communities, plus the truth about each one. The 8th flipchart sheet will list common myths about leprosy which they will want to challenge in their advocacy activities. Ideally participants will keep the flipchart sheets as a resource and the facilitator will take photos/copies of them to be collated for project research. The information written on the flipchart sheets will provide a baseline of knowledge, attitude and perceptions about leprosy against which further activities or interventions can be measured.

Learning Outcomes:

Upon completing this session, participants will:

1. Know the correct answers to the 7 leprosy questions listed in exercise 1.1.
2. Understand real risks around leprosy transmission, and people's misplaced fears about it.
3. Be aware of the myths about leprosy which are prevalent in their communities and know the real facts relating to them.

Time: 2 Hours

Preparation: Study the Module Readings and Appendix 3 "Basic Fact about leprosy".

Materials: 8 Flipchart sheets, marker-pens, cardboard for writing, handout for facilitator, 18 risk activity cards and 15-18 True/False leprosy statement cards (See

Appendix 9). Blue-tac /tape to stick cards to wall /flipcharts. Stopwatch / clock / 3-minute egg-timer.

Method: Interactive and group discussion and tasks.

Source: Adapted from: *“Reducing HIV Stigma and Gender-Based Violence, Toolkit for Health Care Providers in India”*

Exercise 1.1: What we think about leprosy (35 minutes)

Description: This exercise assesses participants’ basic understanding about leprosy. This will help to identify facts, myths or misconceptions and gaps in their understanding, and provide a baseline which future training or discussions can be measured against.

Exercise 1.1: Objective: By the end of this exercise, participants will be aware of the many different understandings of leprosy which exist within their group.

Exercise 1.1: Preparation:

Put up sheets of flipchart paper on the walls with these 7 questions at the top of each sheet (one question per sheet), with two columns underneath on each sheet, the left column much bigger than the right column:

1. What causes leprosy?
2. How is leprosy spread to other people?
3. What symptoms and physical signs are used to diagnose leprosy?
4. What deformities can be caused by leprosy and how?
5. How does leprosy affect family life?
6. How can leprosy be Treated and infection prevented?
7. Is leprosy something to be afraid of, and why?

Exercise 1.1: Activities:

1. Divide the group into 7 pairs or triplets and ask participants to walk around and write down, for each question, in the left-hand column what they think are the answers. Each pair/triplet should start with a different sheet and then move on after 2 or 3 minutes.
2. Then, as a group, review each flipchart paper and the facilitator read out all their answers, with translation as appropriate, so that all members have heard all the answers given. You should expect several different answers for each question!

Guidance:

If working in a group with many people who can’t read or write, then try and make sure each pair / triplet has one member who can write down what the other members say.

Exercise 1.1: Summary:

1. Leprosy is a complicated disease, and over hundreds of years many different beliefs have emerged about it.
2. Although we now know scientific facts about this disease, many of the previous beliefs are still wide spread in our communities.

Exercise 1.2: Ways in which leprosy may be spread. Risk Continuum (35 minutes)

Description: Participants review some different beliefs about ways in which leprosy is spread and assess how much risk they pose.

Exercise 1.2: Objective: By the end of the exercise, participants will be aware of the fears which people often have about catching leprosy and the real (medical) risks related to them.

Exercise 1.2: Preparation:

1. Write up on cards the 18 “Ways in which leprosy may be spread” listed below—one card for each activity, PLUS any other suggested causes of transmission which have emerged during exercises 1.1 and 1.2.
2. Then, write on cards the three risk categories—“HIGH RISK,” “SOME RISK” and “NO RISK”—and tape them across the wall to create a risk continuum.

Exercise 1.2: Activities:

1. Hand out the 18 activity cards to participants and ask them to tape each card under the appropriate position on the risk continuum and briefly say why.
2. Then discuss their choices.
3. Once all 18 cards are there, the facilitator may need to move some of them (from high risk to no risk).
4. He/she should move them one at a time, explaining why each one is being moved and allowing some questions and discussion. (In order to be confident about this, the facilitator should have a printed copy of Appendix 3 with them, which gives answers to these points).

It is important to stress the impact of MDT in changing these risks. Therefore, you may want to have a few red stickers with “MDT treatment” written on them. Adding these MDT stickers to some of the cards will move them. e.g: from “some risk” to “no risk”. The facilitator should explain that this risk transition occurs within two days of starting MDT.

For example: “living in the same house as an infected person” carries “some risk”. However, the solution to this is not to move house, rather to start MDT treatment immediately. This treatment rapidly reduces the chance of spreading leprosy from “some risk” to “no risk”.

Ways in Which Leprosy May Be Spread: Correct Responses

High Risk	Nil
Moderate risk	Living in same house / regular contact with an infected person (who has not yet started MDT treatment) . From the mucus of an infected person coughing and sneezing. (who has not yet started MDT treatment) .
No risk	Spread of leprosy from parent to child (heredity). Shaking hands or touching. Married life. Contact with ulcers. Washing / Bathing someone affected by leprosy. Bathing in the same pond, tank or river. Sharing cups or plates. Breastfeeding. Sharing bed sheets/towels/clothing. Buying food items from someone who has leprosy. Using the same toilets. Mosquito Bites. Going to the same barber / hairdresser. Going to weddings, tea-bars or other crowded places. Being cursed. Eating dried fish and drinking milk.

Exercise 1.2: Summary:

1. Many people fear leprosy because they misunderstand how it is spread.
2. It is actually a mildly infectious disease i.e. difficult to catch!
3. Getting people on MDT as soon as possible is really important, both for curing the person affected and for removing the risk of infecting others.



Exercise 1.3: Distinguishing Facts and Myths about leprosy. (25 Minutes)

Description: This exercise reviews the answers given in Exercise 1.1 and separates the facts from the myths.

Exercise 1.3: Objective: Participants will be able to distinguish the facts from the myths among the beliefs and understandings about leprosy which are prevalent in their communities.

Exercise 1.3: Activities:

Read out the answers on the 7 flipchart papers to the whole group asking members to vote by raising their hand to show if they think each answer was true or false, and tally the votes counted in the second column on each sheet, then for each question give the correct answer and write "True" or "False" next to it in big letters / with a different coloured pen.

Exercise 1.3: Reflection: Ask the group if they are surprised about any of those which are true/false? You may also want to ask them why so many people still believe false ideas about leprosy.

Exercise 1.3: Summary:

1. You now know the truth about leprosy and that so many of the common beliefs about leprosy are false.
2. The stigma experienced by people affected by leprosy is usually based on these false beliefs and fears.



Exercise 1.4: Promoting fuller understanding and confirming lessons learned (25 Minutes)

Description: This exercise tests and consolidates the learning from the previous exercises and gives more detail.

Exercise 1.4: Objective: By the end of the exercise participants will have re-enforced their learning about the understandings of leprosy prevalent in their group and their communities. As well as knowing which are true and false, they will be equipped with answers to the 7 questions and with a list of common misconceptions which they will need to work to overcome.

Exercise 1.4: Activities: To finish the module give the group 15-18 printed statements about leprosy, each on a separate card. Ask them to stick the correct answer-card(s) at the bottom of each of the 7 question sheets and to put any which are false on an 8th sheet of flipchart paper, titled “Myths about leprosy”. (More information can also be found in Appendix 3. “Facts About Leprosy”).

1. Leprosy is a disease caused by *Mycobacterium Leprae* which is only mildly infectious.
2. Leprosy spreads through the mucus of an infected person when they cough or sneeze.
3. The main signs and symptoms of leprosy include: Patches on the skin with loss of sensation, thickening of the nerves, numbness in hands, feet and legs.
4. Leprosy is diagnosed by the doctor examining the patient for signs and symptoms and taking a small scrape of skin to be tested in a laboratory.
5. Leprosy causes nerve damage which can lead to deformities in fingers and toes, foot-drop, inability to close eyes and ulcers on hands and feet.
6. Men and women affected by leprosy can have children and enjoy normal family life while taking MDT and after treatment.
7. Leprosy is treated with MDT for 6–12 months. MDT is FREE at Government health centres.
8. The best way to prevent leprosy is to detect cases early and start MDT quickly. Families and neighbours of new cases should also be tested.

The following **False** statements, or **myths** can be added in, (and you may also choose to add others which are very common in your community).

- You shouldn't use the same cups or plates as someone with leprosy.
- If you have leprosy you should immediately stop working / leave school to stop it spreading.
- People on MDT treatment can still spread leprosy.
- You can get leprosy by going to tea shops, weddings or other crowded places.

- Women have more leprosy germs than men and cause men to catch leprosy.
- Leprosy can be prevented by isolating the people who already have it.
- Leprosy is a punishment for past sins.
- Leprosy can be prevented with sunlight and good ventilation.
- If either of your parents had leprosy than you will definitely get it too.

Exercise & Module Summary:

1. Leprosy is a mildly infectious disease. It can be treated and cured with MDT which is **free of cost**.
2. However, many people still fear leprosy because they believe false things about it.
3. If we want to CURE the disease and DEFEAT the leprosy stigma which people face, then we must first help more people learn the TRUTH about this disease.



Module 2: What is stigma?

Please read out this paragraph as explanation of what stigma is:

Sometimes we treat people badly because we think they have done something wrong; are different in some way from a larger group or because of a disease they have. We isolate or reject them, for example by refusing to sit beside those we think have leprosy; or we gossip about them and call them names. These negative responses and practices are called stigma because they make the person who is treated in this way feel disgraced, even dirty and ashamed.

Stigma means that an individual's or a group's identity is 'devalued' or 'spoilt' because they 'break a norm' or 'possess some distinguishing difference' that carries with it negative meanings that can be considered to be a reflection of poor moral status. These negative meanings can be stronger and weaker in different societies and groups.

Module objective: This module will enable participants to:

1. Understand the ideas of stigma through exploring the forms and effects of leprosy stigma and
2. Name the different situations in which stigma occur in society.

No.	Exercise	Brief description of exercise	Time
2.1	Defining stigma	Provide an explanation of what stigma is	
a	Naming leprosy stigma through pictures	Groups discuss picture cards showing different forms of leprosy stigma as an introduction to the forms and effects of stigma.	
b	Naming leprosy stigma in different contexts or situations	Using the same picture cards in 1 above, groups identify the different contexts in which stigma can occur, e.g. home, workplace, clinic, etc. followed by problem solving	1 hour
2.2	Identifying stigma in different Government establishments	Groups role play problems and challenges that people affected by leprosy face, while accessing services in government establishments	1 hour

Module Output:

At the end of this module, participants would have demonstrated through role plays the problems and challenges that people affected by leprosy face. These role plays can be video recorded and used as resource material on understanding stigma associated with leprosy

Learning Outcomes:

Upon completing this session, participants will:

1. Understand that stigma is part of a social value system about shame and disgrace associated with human difference in a given circumstance.

2. Know that stigmatizing responses (i.e. attitudes and practices) can occur in the home, in the community and in different government departments including in schools, health facilities and social welfare departments etc.

Time: 2 Hours

Preparation: Study the ILEP stigma guide 1 (What is stigma?)

(<http://www.ilepfederation.org/wp-content/uploads/2015/07/ILEP-stigma-guidelines-1.pdf>)

Materials: Flipchart, markers, picture cards, handouts for facilitator, activities

Method: Interactive and group discussions; Role plays

Sources: Adapted from: *“Reducing HIV Stigma and Gender-Based Violence, Toolkit for Health Care Providers in India”*

Exercise 2.1: Naming stigma in different contexts through pictures (1 hr)

Description: This exercise uses picture cards to discuss leprosy-related stigma. It is a useful opening exercise that helps participants to ‘name’ different forms of leprosy stigma and think about the different contexts in which stigma can occur in society.

Exercise 2.1: Objective: By the end of this exercise, participants will know where and how stigma exists.

Exercise 2.1: Preparation:

Select picture cards from appendix 9 of different contexts (e.g. family, clinic, workplace, play ground, tea-shop). Display picture cards on a table or wall.

Exercise 2.1: Activities:

Divide participants into groups of three or four people. Ask each group to select 2 or 3 picture cards and spend 5 minutes to look at and discuss each picture card. The groups should discuss the following questions:

- *What do you think is happening in the picture cards in relation to leprosy stigma?*
- *Why do you think it is happening?*
- *In which context or situation is the stigma happening?*
- *Does this happen in your community? If so, talk about some examples.*

Exercise 2.1 Reflection:

Ask each group to present their analysis of the picture cards they selected under the following broad categories:

- *What are some common forms of stigma across the different contexts?*
- *What are the attitudes/feelings in all contexts towards people with leprosy?*
- *What are the effects on people who have been stigmatised?*

Alternate methods of delivery for exercise 2.1

Show the picture cards to participants and use them to generate discussion. Help them to see what leprosy stigma means in our lives. Instead of criticising participants directly, show them the picture cards and open a discussion using picture cards to discuss how to treat people affected by leprosy.

Exercise 2.1: Summary:

Draw out the main points from the participants' discussion. Make use of some of the points below to add key things which may be missing:

- To stigmatise is to believe that people are inferior; have done something bad or wrong (sinful or immoral behaviour). When we stigmatise we judge people, saying they have broken social norms and should be shamed/condemned; or we isolate people, saying they are a danger/threat to us, for example because of having leprosy. We have been brought up to stigmatise others – to judge or devalue them. We are often not aware that we are stigmatising.
- Stigma is *a belief or attitude*. The action resulting from stigma is *discrimination* – the unfair treatment of people with leprosy, for example sacking an employee or chasing a family out of the house because of leprosy.
- Stigma can be viewed as something normal. It can be seen as something natural, a part of life. People are not always aware of how it affects people who have leprosy and how it affects the spread of leprosy.

**Exercise 2.2: Portraying stigmatizing attitudes in government establishments (1hr)**

Description: This exercise looks at processes involved in accessing services in various government establishments.

Exercise 2.2: Objective: By the end of this exercise, participants will understand that discrimination is a result of stigma; ways of reducing stigma.

Exercise 2.2: Preparation:

Pin up the names of the different Government departments on the walls.

Exercise 2.2: Activities:

1. Divide participants into 4 groups each representing different government departments (hospital, enrolling in a school, social welfare department, participating in a local government council meeting).
2. Ask the groups to perform a role play to show the process of accessing services in their respective establishments.
3. The role play should present stigmatizing attitudes/practices relating to: a) ulcer care in hospital; b) negative treatment of the son of a leprosy affected person in a school; iii) obtaining an identity card in a social welfare department; d) person affected by leprosy participating in a local government council (Panchayat) meeting.
4. After the role plays, ask other groups to mention the stigma attitudes and/or challenges faced by people affected by leprosy in these establishments.

5. Ask participants to discuss:

- *What are the possible effects of the identified attitudes or practices on people affected by leprosy or family members?*
- *Why are these stigma experiences happening?*
- *What can we do to reduce the stigma faced by people affected by leprosy and/or their family members?*

Sample Responses:

Stigma in the clinic environment

- In PHCs, leprosy may not be a priority of the clinic, so they pay little attention to leprosy patients. Not enough staff to give psychological support
- Many steps in the process of diagnosis – no clear information on what to do to complete the process.
- Unfriendly treatment. Harsh and scolding language.
- Delays in providing services—*“We’re on tea break! Come back tomorrow!”*
- Health staff keeps their distance (out of fear) and show their disapproval/ judgemental attitude.
- Health staff gossip about patients. Break confidentiality – e.g. tell families.
- No time to explain things carefully to patients – everything done in a rush.
- Ping pong/bounce from one department to another – this is confusing.
- If patients report late, they are told to go home and come back the following day.

Stigma in community

- Self-stigma: Afraid to tell family and friends about their diagnosis; or afraid to carry their children because of fear of transmitting leprosy to them
- Stigma in family – isolation, questioned about behaviour, finger pointing/blame
- Women blamed and victimised – Thrown out of the house and sent back to her parent’s house.
- Family forces the person to see a traditional healer – looking for someone to blame their leprosy on.
- Neighbours – watching, gossip, come to check on you (nosiness), no real sympathy.
- Communal well or stream – isolation, told to take the water first and leave, so others can gossip.
- Place of Worship – isolation (asked to worship from a separate/designated place away from the other worshippers). Not allowed to participate in any rituals/ communal meals.

Stigma in a school situation

Ask participants to fill in the blanks

Stigma in social welfare department

Ask participants to fill in the blanks

Stigma in participation in local government meeting

Ask participants to fill in the blanks

Examples of how to reduce stigmatizing attitudes and behaviour

- Visit hospitals to discuss with staff with the aim of removing stigma barriers at each stigma point
- Patient family accompany them to hospital to see doctor/HW for counselling

Exercise 2.2: Summary:

- Stigma is part of a social value system about shame and disgrace associated with human difference in a given circumstance.
- This value system causes us to respond negatively towards a person or group that is different in some way from the larger group, by labelling them, calling them names, making them feel inferior and rejecting them based on the assumption or a conscious decision that they break important social norms that bring shame on the family or wider society.
- Stigmatizing responses (i.e. attitudes and practices) can occur in the home, in the community and in different government departments including in schools, health facilities and social welfare departments etc.
- CSOs/Community members can play a vital role in reducing/ ending stigma by creating awareness on leprosy and consciously promoting inclusion of people affected by leprosy.



Module 3: How we stigmatize others

Module Objective: This module enables participants

1. Explore the assumptions which we all make about different groups of people and why we often blame “Others” for many problems
2. Understand and challenge assumptions and attitudes which often lie behind stigmatising behaviour.

No.	Exercise	Brief description of exercise	Time
3.1	We are all in the same boat— Elimination games. Stigma in the center	Groups play a game that leads to elimination or exclusion of players or people who make mistakes as a taster to stigmatization	15 mins
3.2	Things people do or say about people affected by leprosy(including injustices against them)	Groups discuss things we do or say to insult and stigmatize various groups of people e.g. sex-workers, people affected by leprosy etc.	1 hour 30 minutes

Learning outcomes:

Upon completing this session, participants will:

1. Understand that stigmatizing is **also harmful to society as a whole**. If someone with leprosy is stigmatized then they are also more likely to hide their symptoms and delay or avoid treatment, which means they are more likely to become disabled by leprosy and they will remain infectious for longer which increases the risk of others catching leprosy from them.
2. Know that we **should stop judging other people**. All are vulnerable to life’s misfortunes and no one is perfect.

Time: 1 hour 45 minutes (but can be done more quickly if running behind).

Preparation: Study the Module Readings and the ILEP stigma guide 1 (What is stigma?)

(<http://www.ilepfederation.org/wp-content/uploads/2015/07/ILEP-stigma-guidelines-1.pdf>)

Materials: Flipchart, markers, handouts for facilitator, activity cards.

Method: Game, Interactive and group discussion

Source: Adapted from: *“Reducing HIV Stigma and Gender-Based Violence, Toolkit for Health Care Providers in India”*

Exercise 3.1: We are all in the same boat (15 minutes).

Description: This is a warm-up exercise to introduce the idea that the issue of leprosy affects us all. This exercise can be based on any game that eliminates/excludes players when a person makes a mistake. This form of exclusion is a metaphor for stigma, and will be used to trigger discussion on how it feels to be excluded from a group.

Exercise 3.1: Objective:

At the end of this session, participants will recognize that everyone is at risk of being stigmatized, even when they make simple mistakes.

Exercise 3.1: Activity:**Elimination Game: “5-clap”**

Ask players to sit in a circle. The facilitator explains the rules, then asks someone at random to start by saying out loud the number “1”, then the next person says “2”, the next one “3”, and the next one “4” but the fifth person does NOT say “5”. Instead he or she claps their hands (or claps one hand against their leg), whilst saying nothing. Then the next person starts again at “1” and the game continues. Any fifth person who says the number instead of clapping, or who forgets to clap is out and moves into the centre of circle and stays there in silence. If no-one is getting out then speed up the game! After a few minutes several people will be out and sitting in the middle with everyone else staring at them. Once 5 people are sitting in the middle then stop the game.

Exercise 3.1: Reflection:

Ask–

- a) *Those who were eliminated from the game—how did you feel?*
- b) *Those who were not eliminated—how did you feel?*
- c) *What can we learn from the game about stigma?*

Sample Responses:**a) *Those who were eliminated from the game—how did you feel?***

Why me? Anger, Confusion, Embarrassment, I felt I had made a little mistake—didn’t know why I was being eliminated. Why can’t you give me another chance? I felt others were laughing at me. I felt all alone. I felt good when others were eliminated – and then I was not alone. I wanted others to fail—then they would feel the same and join me in the “loser” category.

b) *Those who remained in the game – how did you feel?*

I felt very nervous. I kept watching others to see if they would make a mistake. Yes, I did laugh – it was a natural response – it was a very competitive situation and when someone makes a mistake, you laugh to relieve the tension.

Exercise 3.1: Summary:

- People may like to laugh at and make fun of others, but one day they may also be out of the game, and others will laugh at them. Remember, leprosy can affect everyone.
- Stigmatizing others makes us feel superior to others. It makes us feel that **WE** are right and **THEY** are wrong.
- Yet, as this game shows, **“We are all in the same boat.”** There is no strict separation between **US** and **THEM**. We are all facing and living with this problem together. We are all affected. All of us are at risk of getting leprosy so there is no need stigmatizing or blaming those who are already affected. We could join the many time!
- Don’t point fingers at anyone. As you point one finger toward others, four fingers are pointing back toward you – you are blaming yourself.

Exercise 3.2: Things people say about other different groups of people. (1 Hour 30 minutes)

Description: This exercise explores how we stigmatise other groups, which include people at both the top and bottom of social hierarchies.

Exercise 3.2: Objective: This exercise will demonstrate that all of us tend to stigmatise other groups of people by making assumptions about them.

Exercise 3.2: Preparation:

Setup flipchart stations—blank sheets of flipchart paper on different walls of the room, with the following titles at the top of each sheet: i) People affected by leprosy, ii) People living with HIV, iii) Sex Workers, iv) People who are Transgender, v) Politicians and vi) Beggars, vii) Police, viii) Elderly people. Provide markers at each station.

Guidance:

Select categories that do not apply generally apply to the participants, e.g., do not use the categories “dalits” and “widows” which can be hurtful to participants. Be aware of who’s in your group (e.g. police, politicians, transgender)

Throughout this exercise you should make it clear that these words are being raised **not to insult people, but to show how these stigmatizing words hurt, and how often we all stigmatise others.**

Exercise 3.2: Activities:

1. Divide into eight groups based on the roles assigned for the exercise, and ask each group to go to its flipchart station (e.g., those assigned “people affected by leprosy” role in the warm-up game go to the “people affected by leprosy” station).
2. Ask each group to write on the flipchart all the things people say about those in their assigned group. After two minutes, shout “CHANGE” and ask groups to rotate and add ideas to the list at the next flipchart station. Continue until each group has contributed to all eight flipcharts.

Sample Responses:

THINGS PEOPLE OFTEN SAY ABOUT (these are negative perceptions which are often expressed, not the opinions of the Project team).

People affected by leprosy: Sinners. Untouchable. Keep separate from community

People living with HIV: Promiscuous, Sinners, Irresponsible, Walking graves, Cursed, They got what they deserved, Useless, AIDS untouchable, Unlucky.

People who are Transgender: Promiscuous. Sinners. Immoral. Unnatural. Aggressive beggars.

Sex workers: Whores(moonda), Bitches(veshya), Highway girl, Overnight girl, Promiscuous, Sinners, Immoral, Cursed, Women without shame, Like money.

Politicians: Greedy, corrupt, liars & cheats. They manipulate people and make false promises.

Police: Corrupt, rude, violent & aggressive.

Beggars: Dirty. Nasty. Bad smell. Lazy. Thieves.

Elderly People: Proud, stubborn, resistant to change, don't listen to younger people, irritable.

Exercise 3.2: Reflection:

Bring the group into a semi-circle and ask one person to read the words in each of the lists. Then discuss:

- a) *Have you ever called people these names?*
- b) *How would you feel if you were called these names?*
- c) *What would you do if you were called these names?*

Sample Responses:**How would you feel if you were called these names?**

Ashamed, Embarrassed, Hurt, It makes me very sad, I wish I could die, Bad, Humiliated, Hopeless, Angry, Rejected, Unfairly treated.

What would you do if you were called these names?

I would hide so I wouldn't have to face this kind of rejection. I would lose confidence and stay away from people.

Exercise 3.2: Module Summary:

1. We are brought-up to label other people, often as children we hear these things said by our parents or by our classmates at school. We judge people based on assumptions about their behaviour, whether or not they are true, even if we don't know them personally at all.
2. People affected by leprosy are often labelled as cursed even though leprosy is a bacterial infection, like TB, which can be treated and cured.
3. People living with HIV, sex workers and Transgender people are often labelled as sexually immoral. They are called "promiscuous," "sinners," "irresponsible," without thinking about the different circumstances which led them into their current situation.
4. Beggars also are judged with insulting words such as "dirty," "untouchable," "HIV carriers," etc.
5. Policemen, Politicians and other Public Servants are often decent, hard-working and honest people who serve their communities well. Think about a traffic policeman in a busy city who stands on a round-about all day in the heat and dust, with blaring horns and vehicle smoke. We should praise them for doing this work, not label them, just because some other policeman somewhere else might have done some bad things.
6. When we stigmatize, we stop dealing with people as human beings. Mocking or belittling others gives us a feeling of power and superiority, which might make us feel good. How many of you were laughing during that exercise?
7. We attribute characteristics to a group and everyone who belongs to that group. We assume that all members of the group have the same characteristics, e.g. all people living with HIV are promiscuous. All politicians make false promises. Yet how often do we know any facts about any of these people?
8. Stigmatizing words are like a knife—they have huge power to hurt and humiliate people.

9. Double stigma: Some groups of people are already stigmatized for coming from a certain caste or occupation. These groups face double stigma if they are then also affected by leprosy or HIV or disability. This double or multiple stigma can also be worse for women who are often stigmatised more than men.
10. Historically people from Scheduled castes were not respected, yet people in these groups make important contributions to our society. People should be accepted and respected, not stigmatized whatever their caste, social status or occupation.
11. Stigmatizing people based on the group they belong to is harmful to them because it stops treating them as unique individuals. It is also harmful to society as a whole. If a young, honest and hardworking policeman is always faced with people assuming that he is dishonest or corrupt and treating him badly then he is more likely to become that way himself. If someone with HIV is stigmatized then they are more likely to hide their status and risk infecting others. If someone with leprosy is stigmatized then they are also more likely to hide their symptoms and delay or avoid treatment, which means they are more likely to become disabled by leprosy and they will remain infectious for longer which increases the risk of others catching leprosy from them.
12. Stigmatizing others through group labels is not acceptable. We should stop judging other people. We are all vulnerable to life's misfortunes and none of us is perfect. We might be in one group today, but in a different group tomorrow. Certainly most of us will end up in the group of Elderly people at some point!

Remember:

It is not **WHO** I am or which group I belong to, but **WHAT** I do and **HOW** I behave which really matters!



Module 4: How it feels to be stigmatized

The way we feel when we are stigmatized depends on the situation we find ourselves at a particular time and place. So, stigma will not be experienced in the same way every time. It will change depending on the situation we find ourselves. For example, the way we feel about being stigmatized might be triggered by how someone looks at us, or by their thoughts about us when they look at us. Looking at someone, hearing about them, talking about them, and physical abuse of the person can all generate feelings of being stigmatized.

Module objectives: This module enables participants;

- 1) Empathize with people and their feelings when they are stigmatized and
- 2) Recognize the effects of stigma including psychological and emotional effects on people affected by leprosy.

No.	Exercise	Brief description of exercise	Time
4.1	General reflection on how does it feel to be stigmatized?	Using non-leprosy related examples, participants appreciate what it feels like to be stigmatized	1 hour
4.2	Leprosy-related reflection on how it feels to be stigmatized	Following a testimony by persons affected by leprosy, participants discuss how it feels to be stigmatized due to leprosy	1 hour
4.2a	How men and women experience leprosy stigma (double stigma)	Participants discuss differences in how men and women experience leprosy stigma.	
4.2b	How people with visible deformities experience stigma	Participants discuss possible differences in people with leprosy-related disability experience stigma compared to those	
4.2c	How family members of people affected by leprosy experience stigma (stigma by association)	Participants discuss what it feels like to be stigmatized because of their relation to someone affected by leprosy	

Learning outcomes:

Upon completing this module participants will:

1. Understand how traumatizing it is to be stigmatized; the feelings of being stigmatized are often the same irrespective of whether we are stigmatized because of leprosy or for other reasons
2. Know how stigma reduces/destroys self-esteem

Time: 2 hours

Preparation: Study the Module Readings and read Appendix 4.

Materials: Flipchart paper, makers, handouts for facilitator, activities

Method: Personal testimonies, interactive and group discussion

Sources: Adapted from: *“Reducing HIV Stigma and Gender-Based Violence, Toolkit for Health Care Providers in India”*

Exercise 4.1: Personal testimonies of being stigmatized—not linked to leprosy (1hour)

Description: This exercise helps participants to reflect on personal experiences of being isolated or rejected in situations which are not connected to leprosy; and then share a testimony of how it felt to be stigmatized.

Exercise 4.1: Objectives: By the end of the exercise, participants will be aware of how it feels to be stigmatized for having some difference that is not leprosy.

Guidance:

This exercise is one of the most important because it draws on personal experiences to bring out the feelings of being stigmatized. The exercise requires a lot of trust and openness within the group, so it should not be done at the start of the training. Wait until participants are comfortable with each other, so that everyone can talk openly about their experience and how it made them feel. The facilitators can help participants get started by sharing their own stories and feelings first.

Set a quiet, serious tone for the exercise. Try to minimize outside interference. Keep the door closed so no one can come in and disturb the group’s concentration. Sharing one’s story is voluntary. No one should be forced to give their story. Encourage group members to listen carefully to each other’s stories.

If possible, ask participants beforehand, to bring along a written story of their experience of being stigmatized. If not possible, then ask participants during the workshop to reflect on their experience of stigma.

Exercise 4.1: Activities:

1. General reflection on experiences of being stigmatized (1 Hour):

- a) **Ask participants to:** *Think about a time in their life when they felt isolated or rejected for being seen as different from others—or when they saw other people treated this way. Explain that this does not need to be examples of leprosy stigma—it could be any form of isolation or rejection for being seen as different e.g., albinism.*
- b) **Ask them:** *What happened when you were stigmatized? How did it feel to be stigmatized? What impact did it have on you? Did this include psychological and emotional impacts? If yes, please share this with us.*

Sample Responses : Stigma and discrimination not due to leprosy

Experiences of being stigmatized

Caste discrimination, Experience of being widowed, Woman being rejected by her husband, Visible skin disease resulting in being shunned (albinism, psoriasis).

How did you feel when you were stigmatized?

Depressed, Rejected, Judged, Outcast, Lonely, Second class citizen, Pushed down, Unaccepted, Useless, Failure, Hated, Discredited, Misunderstood, Teased, Insulted.

Exercise 4.1: Reflection:

Ask: *What were the main forms of stigma identified in the stories?
What feelings are associated with stigma?*

Answers are jotted down on the paper, so the facilitator can collect the papers

Exercise 4.1: Summary:

- The feelings of being stigmatized include: shame, feeling rejected, feeling insulted discredited by others, depression, anxiety, suicidal thoughts etc.
- The feelings are very painful and may last a long time

**Exercise 4.2: How it feels to be stigmatized because of leprosy (1 Hour)**

Description: This exercise helps participants to reflect on personal experiences of being stigmatized due to leprosy; and to share a testimony of how it feels to be stigmatized.

Exercise 4.2: Objective:

By the end of the exercise, participants will appreciate what it feels like to be stigmatized due to leprosy.

Exercise 4.2: Preparation:

Identify volunteers (Preferably one male and one female) from the participants/local community affected by leprosy comfortable to give their testimony.

Exercise 4.2: Activities:

- Invite one man and one woman** (who have agreed) to share their stories of being stigmatized due to leprosy. The facilitator may choose to use his/her own story first to break the ice.
- Ask them** to consider –*How they felt; whether they had leprosy-related disability; How this feeling of being stigmatized affected their life? Did this include psychological and emotional impacts? If yes, please share this with us.*

Sample Responses: Stigma and discrimination due to leprosy in the story:

Self-stigma

- Felt ashamed to tell family members and friends of my disease for fear that they may exclude me from family activities or decision making.

Stigma in the family

- Verbally abused by other family members
- Blamed for husband's infection by my mother-in-law.

Stigma in the community

- Neighbours gossip once they discovered I have leprosy.
- People stopped buying goods from the family shop.
- Neighbours stopped their children playing with her son.
- Stigmatised when taking public transport
- Stigma in the health facility, and other government establishment

Exercise 4.2: Reflection

Ask: What were the differences in the man's and woman's experiences of stigma? What should/would be your responsibility and response in similar situations?

Sample Responses: How men and women experience stigma in the story:

Men's experiences of stigma

- May not have a bride to marry
- He will not be invited to participate in decision making in family

Women's experiences of stigma

- Women are usually blamed for husband's disease
- They Feel is unlucky (because of ...)
- They are not invited to major or important occasions
- More likely to be divorced by spouse

Guidance on addressing psychological and emotional impact of stigmatization:

As stigmatization and discrimination may affect people's inner well-being, including having psychological and emotional impacts on them, please refer to Appendix 4 for guidance on addressing the impact of leprosy on people's inner well-being

Exercise 4.2: Summary:

- The feelings of being stigmatized are often the same irrespective of whether we are stigmatized because of leprosy or for other reasons.
- These feelings are very painful. People get badly hurt.
- The feelings of being stigmatized last a long time. These can sometimes lead to more serious mental health problems, for which more guidance can be found at Appendix 4.
- Stigma destroys people's self-esteem. People begin to doubt and hate themselves. They feel alone at a time when they need the support and company of others.
- This exercise put us in the shoes of people affected by leprosy. It helps us understand how painful it is to be stigmatized. People affected by leprosy go through this experience every day of their lives, and it is very demoralizing.
- Women often experience greater stigmatization than men.
- People who have visible deformities experience worse stigma than those without deformities.



Module 5: Understanding Human Rights

Module Objectives: This module enables participants to;

1. Understand how needs and rights are interconnected and why people affected by leprosy have specific rights
2. Understand that discriminating against people affected by leprosy is a violation of rights and such discriminations need to be addressed
3. Appreciate and use the instruments that support redressal of discriminations (Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy; Report 256 & EDPAL draft bill)

No.	Exercise	Brief description of exercise	Time
5.1	Assessing baseline understanding of rights within the group	Brainstorming around what participants think are the needs and rights of persons with disability and persons without disability	40 minutes
5.2	Understanding of specific rights of people affected by leprosy in their communities	Game: Highlighting the specific rights and responsibilities and linking these rights/responsibilities to the Rights for Persons with Disabilities (RPD) bill	40 minutes
5.3	Understanding Human Rights Instruments that safeguard and promote the rights of people affected by leprosy and its use in addressing violation of Human Rights	Explanation of the discriminatory laws that exist; Pamphlets on Principles and guidelines (P&G) for eliminating stigma & discrimination against people affected by leprosy & recommendations of Report 256; Group discussions and presentations on addressing discriminations through case studies; Optional- Screening of the film ‘Unwanted’	1 Hour 10 minutes + Extra 40 minutes if film is screened

Module Outputs:

At the end of this module, participants will have handouts in the form of booklets/pamphlets on Human Rights, Fundamental Rights, the RPD Bill, Report 256, Principles & guidelines on eliminating stigma against people affected by leprosy which they can disseminate among their communities.

Learning Outcomes:

Upon completing this session, participants will:

1. Understand why and how we should safeguard rights/ address violation of rights

Time: 2 Hours 30 minutes + Extra 40 minutes if film is screened

Preparation: Study the Module Readings and the various subsections of Appendix 5 namely 5(A): Understanding Human Rights; 5(B): Fundamental Rights; 5(C): UNCRPD and RPD bill 2016; 5 (D): Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy, 5 (E): Report 256 & EDPAL draft bill.

Materials: Flipchart paper, markers, board, pamphlets on Human Rights, Fundamental Rights, UNCRPD, RPD bill, Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy, Report 256, film ‘Unwanted’, laptop, projector.

Method: Interactive and group discussion and tasks.

Source: Adapted from: *“Combating Exclusion” by Disability Unit-ActionAid India*

Exercise 5.1: Assessing baseline understanding of rights (40 minutes)

Description: This exercise will explore people’s understanding of the rights of individuals with and without leprosy, build on it to gain a deeper understanding of human rights for all, with or without disability.

Exercise 5.1: Outputs:

At the end of this exercise, the group will produce 2 flipchart sheets of paper, the first detailing human rights and the second about Fundamental Rights.

Exercise 5.1: Objectives:

Upon completing this session, participants will:

1. Understand the need of human rights for all
2. Gain awareness on human rights and Rights guaranteed by the constitution-constitutional rights

Exercise 5.1 Preparation:

Facilitators read up and familiarise themselves with various rights by reading appendix 5. Pamphlets on the various rights are made available in the local language.

Exercise 5.1: Activities:

1. Put up 2 charts of papers—one titled ‘Needs of people in the community’ and the other titled ‘Needs of People affected with leprosy’.
2. Divide participants into smaller groups of 2-3 members
3. Ask each group to list the needs of people in the community (non-disabled) on cards. In addition, they should read out their responses and stick the card on chart paper 1.
4. Ask the same groups to list the needs of people affected by leprosy on cards. In addition, they should read out their responses and stick the card on chart paper 2.

Sample Responses:

Needs of people in the community	Needs of people affected by leprosy
Food, clothes, Shelter, education, Employment, companionship. Recreation, equality, opportunity, voting Marriage, public life, work, games	MCR footwear, Mobility aids, Assistive devices, Treatment, Surgery, Therapy, Care, Pensions, housing

Guidance regarding sample responses:

- If participants include the same needs for those affected by leprosy as those for other people in the community in their response, then commend them on thinking along those lines and continue with other needs that have not been included for those affected by leprosy.
- Facilitate the participants to understand and analyze the difference between the two lists of needs.
- Ask them - Do you think People with leprosy also require the needs which you have listed for other people in the community? Do you think People with leprosy are also human beings like the other people in community? Then how come there is so much difference in needs? Do you agree that their needs are also like others? Do you think they have special or additional needs? Why? If not, why not? Just because they are also ordinary human beings like others?
- Ask them what is a right?
- They may come up with examples of rights such as Right to education, livelihood, expression, movement, equality, freedom, religion, culture, participation etc.
- Ask them to remove the word or phrase “right” from the examples, which they have given for a right and see how they look like. For example: education, livelihood, movement, freedom, culture etc.
- Ask them what are these? They may say these are needs of human being.
- Explain how Constitutional Rights find their genesis in Human Rights and introduce Fundamental rights as rights guaranteed by our Indian Constitution.
- Label a chart paper – Human rights and another chart paper – Fundamental rights and encourage responses from the group to list human rights and constitutional rights.
- Distribute pamphlets on these rights and use these to list Human and Fundamental rights.

Exercise 5.1: Summary:

Right is nothing but a **need**. When a *need is legalized or enforced through a law* then a **need becomes a right**.

Human beings are entitled to a set of rights by nature called human rights.

As a citizen of a country, we are entitled for a set of rights guaranteed through our Country’s Constitutional known as Fundamental rights.

**Exercise 5.2: Understanding specific rights and responsibilities of people affected by leprosy (40 minutes)**

Description: This exercise helps participants understand what specific rights are and why they are needed.

Exercise 5.2: Objective: By the end of this exercise participants gain an understanding on the special rights and provisions for individuals with disabilities (more specifically those affected by leprosy).

Exercise 5.2: Preparation:

Clear a space of approximately 15mts x 15mts on one side of the training venue. Keep a few appliances like wheelchairs, crutches, walking sticks at one end of this cleared space.

Exercise 5.2: Activities:

1. Ask for 5 volunteers from within the group to line up on one side of the cleared space.
2. Blind fold and bind the legs of 2 of the 5 volunteers.
3. Place some books about 10 metres away.
4. Then ask these 5 volunteers to go and get the books that are 10 metres away.
5. The two volunteers whose legs are bound and are blindfolded will struggle to do so.
6. Now repeat the exercise by stating that 2 of the books are specifically for the ones who are bound and blind folded.
7. Also, inform the group that those 2 books must be taken by the volunteers bound and blind folded and the group needs to ensure that the volunteers go and get those books. They are free to use the appliances or any equipment they want
8. The group may help by carrying the volunteers, making them sit on the wheelchair and taking them there.

Exercise 5.2: Reflection:

1. Ask the group to analyse the two situations—the first situation when nothing was reserved for those bound and blindfolded (relate this to people affected by leprosy with disabilities) and the other situation, when there were 2 books reserved for them plus assistive devices and caregivers were available.
2. Link the special provisions needed (reservation, assistive devices, caregiver) in the exercise to specific needs of people affected by leprosy and hence the need for specific rights for people affected by leprosy.
3. Talk about the RPD Act 2016 and what are the specific rights guaranteed under the RPD Act for people affected by leprosy.

Exercise 5.2: Summary:

The RPD Act 2016 guarantees the rights of people with disabilities including people affected by leprosy

It is the responsibility of the Government to ensure that these rights are available to all people affected by leprosy



Exercise 5.3: Understanding Human Rights Instruments that safeguard and promote the rights of People affected by leprosy (1 hour and 10 minutes + an extra 40 minutes if the film is screened) and its use in addressing violation of Human Rights

Description: This exercise unpacks the various instruments available that help identify and address violations and discrimination (Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy; Report 256 & EDPAL draft bill). The exercise uses case studies to highlight violations of rights (i.e. How people affected by leprosy are discriminated against) and help the group identify what steps can be taken to address such violations.

Exercise 5.3: Objectives:

Upon completing this exercise, participants will be able to:

1. Understand how the various instruments promote access to rights
2. Recognise how the rights of persons affected by leprosy can be violated and suggest ways of addressing such violations

Exercise 5.3: Preparation:

Read case studies of examples of violation of rights of people affected by leprosy as detailed below, Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy and Report 256, organize projector and laptop to screenfilm 'Unwanted' in local language, pamphlets on important issues in Principles & Guidelines for eliminating stigma & discrimination against people affected by leprosy, Report 256 and EDPAL.

Exercise 5.3: Activities:

1. Introduce the various instruments that the Government of India (GoI) has ratified to ensure the specific rights of people affected by leprosy.
2. Use pamphlets to describe various rights and guidelines recommended in the following instruments:
 - Principles & Guidelines on Elimination of discrimination against persons affected by leprosy and their family members and
 - Report 256 & EDPAL bill and how they reinforce RPD.
3. After the above have been discussed, ask a participant to summarise the same.
4. Divide the participants into groups of 2-3 people and to each group, give one of the following case studies to read
5. Ask the groups to analyse the case studies in the light of rights – Human Rights, Fundamental Rights and Special Rights.
6. Each group is given 20 minutes to identify the rights that have been violated and recommend actions to address these violations

And (Optional)

1. *Introduce the film titled 'Unwanted' and play the DVD of the film (in local language). (This is optional if your community setting doesn't have a screen/power supply). (If the film is introduced as part of the module then the module will require an additional time of one hour).*
2. *Ask group members to identify instances in the film where the rights of the person affected by leprosy were violated and write such instances on a chart paper.*

Case Studies:

1	Mohan worked as a painter and used to paint statues of Gods in local temples, murals and houses. Mohan was very good at his work. He worked with in his friend, who was running the painting business. Mohan was efficient and hardworking, which was admired by his colleagues and also his friend. After few months, Mohan was diagnosed with leprosy. However being unaware of the disease he delayed treatment and ended up with deformities. Once his colleagues and friend knew that Mohan was affected by leprosy they started avoiding him. Fear that the disease will spread to them as well, made his colleagues force Mohan's friend to relieve him of his current job. The news that Mohan is affected with leprosy was also spread to many others within the community. It became difficult for Mohan to seek employment at other places as well.
---	--

2	Geeta and her husband were happily married until Geeta found out that she has a patch on her hand. She consulted a local doctor (Vaidya) but nothing helped. A few days later she went to a government hospital, they diagnosed her with leprosy. As soon as the husband and his parents realised she has leprosy, they threw her out of the house as they feared she would spread the disease to other family members. They later forced Geeta to sign the divorce papers.
3	<p>Awdesh is the eldest son among 6 siblings. Awdesh was affected by leprosy. Being unaware of the disease his treatment was delayed and he ended up developing deformities in his left hand. He has since completed his MDT treatment and has also undergone corrective surgery to correct his deformity of the left hand.</p> <p>He is in class 9 and loves going to school. However, he has been asked to sit separately in the class room, as he is affected by leprosy. The Teachers have instructed him not to sit or interact with his classmates as he will spread his disease leprosy by doing so. Other children have also been told to avoid Awdesh and stay away from him. Children also avoiding his other siblings studying in the same school.</p>
4	Manav has completed his leprosy treatment. He wants to participate in the local Gram Sabha meetings and aspires to contest the Panchayat elections. However, when he goes for the Gram Sabha meetings, he is asked to stand outside the hall and no one interacts with him. He has been told that because of his leprosy he will not be allowed to contest elections.
5	Rambha stays with her grandmother ever since she lost both her parents. She was diagnosed with leprosy a year ago and has been taking treatment regularly. As her cousin was getting married the whole family took part in the celebration. While, Rambha desired to be part of the celebration, her relatives asked her to stay away from the ceremonies, as they feared that her leprosy status will cause problems/hindrances in the marriage of her cousin.

Exercise 5.3: Reflection:

Based on the Case Studies

- Ask groups to present (on a flip chart paper) which right was violated in their case study
- Ask each group to recommend possible actions that need to be taken to redress the violated rights and how the actions can be taken in such a situation.

Based on the film 'Unwanted'

- Ask groups to present (on a flip chart paper) which right was violated in the film
- Ask each group to recommend possible actions that need to be taken to address such violations.

Exercise 5.3: Summary:

- Principles & Guidelines on eliminating discrimination against people affected by leprosy is an important international instrument ratified by the Government of India. It details measures that the State should adopt to ensure that people affected by leprosy are not discriminated against.
- Report 256 is a detailed report put together by Law Commission (with support from TLMTI) that highlights stigma and discrimination faced by people affected by leprosy across India.
- EDPAL is a draft bill at the end of Report 256 entitled 'Eliminating Discrimination Against Persons Affected by Leprosy Bill, 2015' (EDPAL draft bill), which is still

waiting to be taken through the law-making process. EDPAL firstly addresses the legal provisions in existing laws that have direct or indirect discriminatory effect on people on the grounds of leprosy. And secondly, the need for affirmative action not only for people affected by leprosy but also their family members who suffer the effects of the stigma associated with leprosy.

- The Bill has built in provisions for protection from discrimination in all facets of human life from i) inclusion in society to ii) education, iii) employment, iv) healthcare, v) use of goods and services, and vi) ownership rights and vii) freedom of movement. The Bill also addresses the use of derogatory terms like 'Leper' and specifies its removal from all official usage. It also covers a range of affirmative provision including education, health, employment, social security, movement, land ownership in leprosy colonies, awareness generation.
- Go through each group flip chart on analysis of the Case Study and summarise the actions that can be taken, **focussing on the 'what' and 'how'** of the action.



Module 6: Action towards inclusion of people affected by leprosy

This module helps participants to think deeply about concrete strategies for action. It assumes that participants have already discussed leprosy-related stigma in their community and are committed to doing something to change things. Developing a plan will further increase commitment of the participants to bring about a change and to put an end to stigma and discrimination.

Module Objective: This module enables participants to

1. Review the current situation concerning leprosy-related stigma and develop a vision of a community without stigma and discrimination
2. Develop an action plan for ensuring inclusion of people affected by leprosy.
3. Identify specific activities towards that vision/action plan.

No.	Exercise	Brief description of exercise	Time
6.1	Collating the lessons learned from Modules 1 to 5 of toolkit	Participants identify how key lessons from the toolkit apply to their community. Lessons may be identified by revisiting module outputs generated and/or resource materials used during modules 1 to 5.	30 minutes
6.2	Disseminating lessons learned to community through social communication and advocacy	Participants use awareness programmes and advocacy initiatives to disseminate lessons learned from modules 1-5 to the broader community.	30 minutes
6.3	Using a "BEFORE" and "AFTER" picture to create an understanding of what a Community free of Stigma and discrimination would look like	Participants sketch a poster of the current situation of leprosy-related stigma in their community, followed by a poster of a community where leprosy related stigma and discrimination does not exist.	45 minutes
6.4	Developing action plan to counter stigma & discrimination in the community	Participants discuss community initiatives to undertake for reducing stigma in their community (including awareness campaigns, empowerment, advocacy, training and livelihoods/employment). Identify actions (activities) that will be undertaken with the community to reduce stigma	45 minutes

Module output:

The participants will come up with an action plan that will help them move towards making their community stigma- free.

Learning Outcomes:

Upon completing this module, participants will:

1. Know how CSOs can make their community stigma free and work towards it.

Time: 2 hours 30 minutes

Preparation: Study the Module Readings and Appendices 6, 7 and 8, refer ILEP guideline 3 (<http://www.ilepfederation.org/wp-content/uploads/2015/07/ILEP-stigma-guidelines-3.pdf>)

Materials: Flipchart sheets, marker-pens, cardboard for writing, picture cards.

Method: Interactive and group discussion and tasks.

Source: Adapted from: *“Reducing HIV Stigma and Gender-Based Violence, Toolkit for Health Care Providers in India”*

Exercise 6.1: Lessons learned from Modules 1-5 (30 minutes)

Description: This exercise will help participants reflect on and identify how lessons learned from modules 1-5 apply to their community.

Exercise 6.1: Objective: By the end of this exercise, participants would have recapped the key learnings of modules 1-5.

Exercise 6.1: Activities:

Using the same groups as in exercise 5.2, ask participants to reflect on the exercises from modules 1 to 5; and identify lessons learned.

1. Ask participants how the lessons apply to their community?

Sample Responses (of lessons learned):

- a) New knowledge and awareness about leprosy
- b) Changed attitudes
- c) Behavioural changes needed (both personal and communal).

Knowledge:

- Leprosy is curable with MDT.
- How leprosy is spread and not spread, and our misconceptions are answered.
- People affected by leprosy face stigma everywhere—at home, clinic, workplace and in Government establishments.
- People affected by leprosy are not the only stigmatized group in society.
- Women face more stigma than men—and also face gender related discrimination.
- People affected by leprosy have rights and responsibilities.

Attitudes:

- We should treat people affected by leprosy with respect and affection.
- Discrimination is not just a family issue; it is a social problem that we should all try to deal with.

Behaviour change:

- No longer isolate people affected by leprosy. Support and encourage them.
- Share key learnings with family members, neighbours, women’s groups, .etc.
- Inform leprosy patients that leprosy is a curable disease and support them in seeking treatment.

Exercise 6.1: Reflection:

Ask each group to present their lessons learned or identified

Exercise 6.1: Summary:

The objectives and learning outcomes for modules 1 to 5 are reinforced.

Exercise 6.2: Disseminating lessons learned using social communication and advocacy(30 minutes)

Exercise 6.2: Description: This exercise uses social communication and advocacy methods to share lessons learned from the toolkit to the wider community.

Exercise 6.2: Objective: By the end of this exercise participants will be able to list the various instruments that will aid communication and advocacy

Exercise 6.2: Preparation: Put up the definition of social communication and advocacy on a wall. Keep flash cards ready for various ways of generating awareness.

Definitions:

1. Social Communication is generally referred to awareness generation programmes in the community on various issues.
2. Advocacy is collective action to help you express your views and wishes, and to help make sure your voice is heard. Someone who helps you in this way is called your advocate.

Exercise 6.2 Activities:

1. Explain the definitions of “Social Communication” and “Advocacy” before starting the exercises
2. Ask the participants to list down the various methods of awareness generation. They may list the following: Street Play, Puppetry, Poster, Radio, TV, Newspaper, Public speech, Film show, Wall writing, Community meetings etc.
3. As they list the method, put up the picture card for it and ask them to briefly explain the method and the audience for which this method will work best.
4. Ask the participants to list down the various methods of advocacy.
5. As they list the method, write it on a flash card and put it up under the definition of advocacy. Ask participants to briefly explain the method and the audience for which the method will work best.

Sample Responses:

- Rallies
- Conduct a public hearing and debates
- Publishing newsworthy stories
- Lobby decision makers
- Organize protest
- Press conferences
- Write letters

Exercise 6.2: Reflection:

Ask a volunteer from within the group to explain each method briefly as the flash card for it is put up.

Exercise 6.2: Summary:

The various methods of Social Communication and Advocacy are explained and reinforced.

Exercise 6.3: A Community Free of Leprosy Stigma and Discrimination (45 minutes)

Exercise 6.3: Description: This exercise helps participants to visualise and draw a sketch of their community 'Before' stigma has been addressed and then connect that with how it would look 'After' steps have been taken to address stigma.

Exercise 6.3: Objectives:

By the end of the exercise participants will be able to demonstrate the anticipated change in their community after leprosy related stigma is addressed.

Exercise 6.3: Activities:

1. Divide the participants into two groups.
2. Give each group a chart paper where they sketch a "BEFORE" and "AFETR" picture of their vision of a community free of leprosy related stigma & discrimination.

Exercise 6.3: Reflection:

Ask each group to present their "BEFORE" and "AFETR" vision of a community free of stigma.

Exercise 6.3: Summary:

The different ways in which stigma exists in their community is highlighted, ways in which communities can be made stigma free is visualised.

Exercise 6.4: Action planning through CSO case study (45 minutes)

Exercise 6.4: Description: This exercise helps participants to discuss action planning in reducing stigma using a story of a Civil Society Organization, which mobilized their community in addressing the issue of stigma.

Exercise 6.4: Objectives:

At the end of the exercise, participants should be able to

- Identify stigma-related issues that require action in their community
- Suggest initiatives needed to bring about change in stigmatization in the community

Preparation 6.4: read the case story

Exercise 6.4: Activities:

1. Narrate the story (below) of *“CSO members who took action for addressing leprosy related stigma”*.
2. Ask participants to discuss and **identify the issues** in the story, what actions were taken, who took action, and what changes occurred because of the action(s) taken.

Case Study:

Vishaal and his family live in a thatched hut towards the end of their field. Vishaal’s brother threw him out of the house after he was diagnosed with leprosy and developed severe reactions. Vishaal’s wife tried several times to get him treated at the local PHC but they refused to register his case as the Government did not want to show increase in numbers to a disease that was eliminated. Hence Vishaal could not get the required MDT nor be treated for his reactions. He suffered a lot physically. His two sons were strictly instructed by the school not to mingle with the other children. They were asked not to drink water from the school tap. Vishaal’s wife, left with no support toiled alone on the field given to them to support the family. She had to travel 10kms to sell her produce as none from her village bought it. Life was unbearable.

A CSO in the neighbouring village heard about Vishaal and came to his aid. Members took Vishaal to the PHC and demanded why he wasn’t treated. They threatened to take up the hardships Vishaal was facing as a case of gross negligence from the PHC. The PHC tried to wash their hands off by saying that they had no MDT and did not know how to treat reactions. The CSO members asked the PHC to give them a written statement to this effect. The PHC finally agreed to make MDT available in the next 2 days and referred Vishaal to a TLM hospital for his reactions. One of the CSO members agreed to take Vishaal with him. Vishaal was admitted at the hospital and his treatment started. The CSO members ensured that the PHC delivered the MDT to Vishaal at the TLM hospital. The CSO organized a community meeting and used local theatre to demystify the fears surrounding leprosy. They went to the school and filmed a movie about leprosy. The school administration and children immediately pledged that they will not stigmatise against Vishaal’s children and also promised to spread further awareness on leprosy in the village. The PRI who was educated on leprosy summoned Vishaal’s brothers and warned them that if they did not give Vishaal and his family what is rightfully theirs, they will have to answer to the Village Panchayat. The school children took out a rally in the village asking people to support Vishaal and his family. The CSOs also organized wall writing at select spots in the village so that correct information on leprosy could be communicated. They encouraged villagers to buy the produce from Vishaal’s field and set an example by buying it first. The CSO also got a screening camp organized in the village and 4 adjoining village in which 3 new cases were diagnosed.

Exercise 6.4: Reflection:

Ask participants

- a) *What issues pertaining to leprosy related stigma did you identify in the story?*
- b) *What initiatives/activities did the CSOs undertake to address the issues identified?*
- c) *How did the CSOs organize and mobilize action to reduce stigma in their community?*

Action planning for community

- a) *Think about stigma issues you identified in the “BEFORE” picture sketched in Exercise 6.3,*
- b) *What initiatives/activities will you undertake to change the “Before” picture to the “After” picture in your community (based on exercise 6.1 & 6.2 and actions from the case study)?*
- c) *What resources do you require to implement the initiatives?*
- d) *Which duty bearers and other stakeholders will you work with to achieve a stigma-free community?*

Exercise 6.4: Summary:

- Action plan for a leprosy related stigma free community is understood and chalked out
- Although CSOs and Field Workers can identify stigma issues that require change in their communities, they cannot organize against stigma on their own. They need support from duty bearers and other stakeholders to make a real impact.
- If everyone works together in organizing community meetings, people will listen and dramatic changes can result.
- There are several initiatives and activities needed to counteract stigma (i.e. to change beliefs, attitudes and negative practices). The initiatives include a) awareness raising of community members, b) empowerment of people affected by leprosy, c) management of impairments and deformities d) advocacy to duty bearers, e) education, training and livelihoods/employment.
- Organizing the community against stigma and implementing initiatives to achieve a stigma-free community requires careful and orderly planning for change.
- See the next page for a table of “8 Essential Steps for Action Planning” to guide CSOs and communities in carrying out action planning to achieve real impact. The table shows questions and explanations of what CSOs and communities need to do at each step of action planning to achieve a stigma-free community.



Essential Steps in Action Planning for a Stigma-free Community

Steps in Action Planning	Explanation
1. What is the current situation regarding leprosy-related stigma in your community? (Situational Analysis)	This helps community members look at what is currently happening concerning stigma. You can ask: "How have things been in the past?" and "How are they now?" What are the common forms of stigma in the community? What background factors influence stigma? etc. You may refer to your "BEFORE" sketch for exercise 6.3. You may also work with field workers to use stigma assessment scales in Appendices 1 and 2 to assess the level of stigma in your community.
2. What do you want the situation in your community to look like in 3 years' time after implementing your anti-stigma initiatives? (Vision)	How would things look if you could make a real difference? You may refer to your "AFTER" sketch for exercise 6.3 in which there is reduced stigma in the community.
3. What activities will you carry out to reach the goal of a stigma-free community? (Activities)	What kind of initiatives and activities can you undertake to help reduce stigma? Discuss ideas with community members to ensure practical actions are selected. Consult ILEP stigma guide 3 for ideas on reducing stigma.
4. Which activities are most important to start with? (Priority setting)	What are the most feasible actions to start with? What is the most important action?
5. What resources do you need to help you undertake your activities? (Resources)	Identify resources, skills or training that will help you with your action . Which duty bearers, community members or partners can help you achieve your goal of a stigma-free community? Which of the resources identified are available in the community or in government departments?
6. How will you know that you are successful in your actions? (Indicators)	What things will show that your community has been successful in its actions? Decide how you will measure your success. Identify "indicators" or signs that will show you that stigma is reduced, e.g., are more people affected by leprosy included in community activities? Do they contribute to decision making?
7. Action (Implementation)	Start implementing activities you have planned. Assign tasks to specific people or groups and attach a timescale for achieving the tasks.
8. Are your activities/initiatives working? (Monitoring and Evaluation)	For monitoring : Ask Is there a difference after you implemented your initiatives compared to some time ago? Check how you are doing against your plans and whether anything is changing and modify your activities if needed to enable you reach your goal. For evaluation : Ask Have the levels of stigma come down following your interventions? Who has benefited from the interventions? See Appendix 1 and 2 for stigma assessment scales. Also consult the ILEP guideline to reduce stigma: "Guide 2" for how to assess stigma.

No:	Participation Scale Compared to your peers . . .	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
			0				1	2	3	5	
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
8	Do you visit other people in the community as often as other people do?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
9	Are you comfortable meeting new people?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
10	Do you have the same respect in the community as your peers?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it for you?						1	2	3	5	
11	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
12	In your village, do you visit all the public places/common places? (including schools, shops, offices, market and tea/coffee shops)		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
13	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
16	In your home, are the eating utensils you use kept with those used by the rest of the household?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
17	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	
18	Do you feel confident to try to learn new things?		0								
	<i>[If sometimes, no or irrelevant]</i> How big a problem is it to you?						1	2	3	5	

Source: van Brakel, (2004)

Comment:

TOTAL

Identification No: _____

Age: _____

Gender: _____

Reason for the assessment: _____

Interviewer: _____ Date of interview: ___ / ___ / ___

Scientific Reading:

- Van Brakel, W.H, Anderson, A.M., Mutatkar, R.K., Bakirtzief,Z., Nicholls,P.G., Raju,M.S., & Das-Pattanayak, R.K.2006. The Participation Scale: Measuring a key concept in Public health. Disability And Rehabilitation,28,(4), 193-203.
- Renson, C. Bandyopadhyay, S.Gopal, P.K & Van Brakel,W.2010. Measuring leprosy-related stigma- a pilot study to validate a toolkit of instruments. Disability and Rehabilitation, 33, (9), 711-719.

2. Stigma Assessment and Reduction of Impact (SARI) Stigma Scale

The SARI stigma scale aims to assess stigma and is based on the HIV Stigma Scale developed by Berger et al. [REF 11]. The scale has 21 items (scored from 0–3, with total scores ranging from 0–63) and four domains. The domains are: experienced stigma (min-max total score 0–21), disclosure concerns (min-max total score 0–12), internalized stigma (min-max total score 0–18) and anticipated stigma (min-max total score 0–12). The cross-cultural validity of the scale was tested in Cirebon District of Indonesia and found to be adequate for the Bahasa Indonesia-speaking population.

SARI Stigma Scale v.1.1 (based on the Berger HIV stigma scale)		No	Yes	Don't know	Not Relevant	Always/ Often	Sometimes	Rarely/once	Score
Experienced stigma									
1a	Do some people who know you have (had) leprosy keep more distance from you?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
2a	Do people you care about stop contacting you after learning you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
3a	Did you lose friends by telling them you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
4a	Do people avoid touching you once they know you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
5a	Have people physically backed away from you when they learn you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
6a	Do people seem afraid of you once they learn you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
7a	Do you feel set apart and isolated from the community since learning you have (had) leprosy?	0		0	0				
B	(If yes) How often has this happened?					3	2	1	
						Subtotal			
Disclosure concerns									
8a	Are you careful who you tell that you have (had) leprosy?	0		0	0				
B	(If yes) How often are you careful?					3	2	1	
9a	Do you feel the need to hide your leprosy	0		0	0				
B	(If yes) How often do you feel the need to hide your status?					3	2	1	
10a	Do you believe telling someone you have (had) leprosy is risky?	0		0	0				
B	(If yes) How often do you believe it is risky?					3	2	1	
11a	Do you worry that people may judge you when they hear you have (had) leprosy?	0		0	0				
B	(If yes) How often do you worry about this?					3	2	1	
						Subtotal			

SARI Stigma Scale v.1.1 <i>(based on the Berger HIV stigma scale)</i>		No	Yes	Don't know	Not Relevant	Always/ Often	Sometimes	Rarely/once	Score	
Internalized stigma										
12a	Do you feel guilty because you have (had) leprosy?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
13a	Do you feel you are not as good a person as others because you have (had) leprosy?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
14a	Are you embarrassed that you have (had) leprosy?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
15a	Does having (had) leprosy make you feel unclean?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
16a	Do you regret having told some people that you have (had) leprosy?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
17a	Does having (had) leprosy make you feel that you are a bad person?	0		0	0					
B	<i>(If yes) How often has this happened?</i>					3	2	1		
		Subtotal								
Anticipated stigma										
18a	Do people affected by leprosy lose their jobs when their employers find out?	0		0	0					
B	<i>(If yes) How often does this happen?</i>					3	2	1		
19a	Are people affected by leprosy treated like a public nuisance?	0		0	0					
B	<i>(If yes) How often does this happen?</i>					3	2	1		
20a	Do most people think that a person affected by leprosy is disgusting?	0		0	0					
B	<i>(If yes) How often does this happen?</i>					3	2	1		
21a	Do most people feel uncomfortable around someone affected by leprosy?	0		0	0					
B	<i>(If yes) How often does this happen?</i>					3	2	1		
		Subtotal								
		Total								

Scientific Reading:

- Dadun, Ruth M.H. Peters, Wim H. Van Brakel, Mimi Lusli, Rita Damayanti, Joske F.G. Bunders & Irwanto. (2017). Cultural validation of a new instrument to measure leprosy-related stigma: the SARI Stigma Scale. *Lepr Rev* 88, 23–42.

Appendix 2: Washington Group Questions on Disability

Washington Group developed an universally comparable measure of disability to identify persons who are at greater risk than the general population of experiencing restrictions in performing certain tasks or participating in roles.

We encourage CSOs to use the 6 Questions below Endorsed by the Washington Group

The questions ask about difficulties with doing activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?

- a. No - no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?

- a. No- no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

3. Do you have difficulty walking or climbing steps?

- a. No- no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

4. Do you have difficulty remembering or concentrating?

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

Please Note:

The questionnaire is available at the following link below

https://www.cdc.gov/nchs/data/washington_group/wg_short_measure_on_disability.pdf

https://www.cdc.gov/nchs/data/washington_group/meeting6/appendix5_interviewer_guidelines.pdf

https://www.cdc.gov/nchs/data/washington_group/meeting6/appendix6_analytic_plan.pdf

Appendix 3: Facts about Leprosy for advocacy and awareness in Communities

1. What is Leprosy?

Leprosy is one of the oldest diseases in recorded history. According to the World Health Organization (WHO), the first written reference to leprosy is from 600 B.C. It is a **chronic disease caused by bacterial infection with *Mycobacterium leprae***. However, Leprosy is one of the least infectious of infectious diseases. More than 85% of cases of leprosy are non-infectious and do not spread the disease. Over 99% of people have a natural immunity or resistance to leprosy. It is NOT a hereditary disease (i.e. one which passes automatically from parent to child, at birth).

Leprosy is common in many countries, especially those with tropical or subtropical climates. Thus, leprosy is seen in Southeast Asia, Africa and South America. India contributes 60% of all known cases world-wide.

2. How does leprosy spread to other people?

Leprosy spreads through contact with the mucus of an infected person. This usually occurs when the infected person sneezes or coughs. The disease isn't highly contagious. Close, repeated contact with an untreated person causes infection, and this risk is increased by poor immunity and unhealthy living conditions (especially regarding nutrition and sanitation). The bacteria responsible for leprosy multiply very slowly. The disease has an incubation period (the time between infection and the appearance of the first symptoms) of up to five years. Symptoms may not appear for as long as 20 years.

3. What are the symptoms and physical signs of leprosy?

The main symptoms of leprosy include:

- **Skin patches or lesions with loss of sensation to touch, temperature or pain.**
- **Thickened nerves and muscle weakness**
- **Numbness in the hands, arms, feet, and legs**

The skin patches or lesions don't heal after several weeks, may be raised and hairless and are lighter than your normal skin tone.

If the facial nerve is affected, a person loses the blinking reflex of the eye, which can eventually lead to dryness, ulceration, and blindness. Bacilli entering the mucus lining of the nose can lead to internal damage and deformity which in time causes the nose to collapse. If untreated, there can be progressive and permanent damage to the skin, nerves, limbs and eyes. There may also be nodules on, or thickening of, the earlobes.

3b. How is leprosy diagnosed?

The doctor will conduct a physical exam to look for tell-tale signs and symptoms of the disease. She/he will remove a small piece of skin and send it to a laboratory for testing. Diagnosis of leprosy can be done at any Primary Health Centre, (PHCs), Community Health Centres (CHCs), District & Sub-district Hospitals (DH & SDH) and Medical College Hospitals. Several NGOs also run programs for the detection and diagnosis of leprosy. The Leprosy Mission Trust India has several community programs that spread leprosy awareness and help in early detection of leprosy. It also runs 14 hospitals to diagnose suspect leprosy cases.

4. What deformities can be caused by leprosy and how?

With early detection and MDT treatment a person can completely recover from leprosy without any deformities. However, if left untreated the leprosy bacilli can damage the nerves, especially the

nerves of the extremities, the lining of the nose, and the upper respiratory tract. Leprosy produces skin sores, nerve damage, and muscle weakness. Left untreated, it can cause disfigurement and result in permanent disability. Foot-drop, clawing of the hands and damage to the eyes due to inability to blink are all caused by leprosy. Ulcers on hands and feet are also common and if left untreated can lead to the loss of fingers and toes.

5. How does leprosy affect family life?

Leprosy is often associated with family breakdown and painful enforced isolation. However, this is completely un-necessary. Both men and women affected by leprosy remain capable of producing children and enjoying normal family-life both during and after treatment with MDT. Because leprosy is NOT hereditary, these children can grow up perfectly healthily and live normal lives.

6. How leprosy treated and infection is prevented?

Leprosy is treated by multidrug therapy (MDT), a highly effective treatment that became available in the early 1980s. MDT is a combination of three drugs administered over a 6- to 12-month period. The first dose of MDT kills 99.9% of the bacteria in the body that cause leprosy. Treatment for Leprosy is available FREE of cost in the Government Health facilities where the patient is registered. Leprosy can be treated at any stage. To be cured of leprosy means to have no leprosy-causing bacteria remaining in the body. If detected and treated at the early stage, no subsequent complications to the disease need occur. However, if leprosy is detected and treated only after permanent nerve damage has occurred, there will be residual disability and disfigurement.

The most effective way to prevent infection is early detection and early treatment (MDT).

7. Is leprosy something to be afraid of and why?

The misconceptions around leprosy which have built up over hundreds of years mean that many people fear it more than most other diseases, even though it is much harder to catch than TB, and much easier to treat than HIV/AIDS or most cancers. Because of the deformities which people see and the social stigma which people affected by leprosy so often experience, many people dread the disease. However, leprosy should not be feared any more than any other disease. It is only mildly infectious, it can be diagnosed with a simple test, the treatment is effective, and the treatment is FREE at government health centres. This makes leprosy less scary than many other diseases!

Other Useful Information and frequently asked questions:

How can we prevent disabilities/worsening of disabilities in people affected by leprosy once they have set?

It is vital to prevent disabilities or their further worsening once they have set in to preserve balance, nerve function and eye-sight and to regain functional ability and self-esteem.

To do so people need to practice self-care (methods to take care of the eyes, hands and feet) and use aids and appliances and specialized footwear as required. Sometimes surgical correction of deformities is needed to restore the use of that part of the body. When ulcers do not heal through self-care practise, their surgical management is required. It is important to ensure that the environment at home and in the work place is disability friendly according to the needs of the individual affected by leprosy to prevent further injury. The consequences of neglecting prevention/worsening of disabilities are great, leading to loss of productivity; deformities and ulcers; stigma; and enormous physical and mental suffering for those affected by leprosy and their families.

Can leprosy be caught from eating certain foods?

There are various myths about leprosy being caught from eating dried-fish, goat-meat etc. But leprosy bacilli are NOT transmitted through food. However, one factor in reducing leprosy transmission is good immunity, and immunity is boosted by a healthy diet, including the vitamins found in fresh fruits and vegetables.

Can leprosy be caught by touching, shaking hands or going to crowded places with infected people?

No. Leprosy is not spread by touch. Refusing to touch people affected by leprosy or excluding them from public/social events is hurtful discriminatory behaviour which does not reduce transmission.

Should people who have been infected with leprosy be made to live separately, bathe/wash separately or use their own cups/plates, sheets and towels?

Leprosy is not spread by touch, taste or through water. It is spread through the mucus released by coughing and sneezing. Therefore, using different household items and living separately are not the way to prevent transmission. The most effective way of preventing transmission is to detect cases early and get them onto MDT treatment quickly.

When Health workers treat ulcers they wear gloves and masks, is this because leprosy is spread through touching ulcers?

No. Leprosy can only be spread through mucus. It is standard practise for health workers to wear gloves and masks when treating any open wound, such as from a vehicle accident, or an ulcer. They do this to protect the patient as much as themselves, because an open wound is an easy route for other infections to enter the patient's body, including germs from the health worker.

Can a mother who has leprosy still breastfeed their child safely?

Yes. Leprosy cannot be passed through breast milk. However, two of the drugs used to treat leprosy (Clofazamin and Dapsone) can affect breast milk, so mothers should get advice from their Doctor about breastfeeding while on MDT.

Can mosquito bites cause leprosy?

No. Leprosy is not transmitted by insects. Mosquito bites can cause malaria, dengue fever and other unpleasant diseases which should be avoided. However, insects cannot spread leprosy.

Please Note:

The Leprosy awareness information is available in the following Link below

<http://tlmindia.org/>

<https://www.leprosymission.org.uk/about-us-and-leprosy>

<https://www.lepra.org.uk/lepra-and-leprosy?gclid=CK-F3J-wjdQCFYQEaAodEPOCNw>

<http://www.webmd.com/skin-problems-and-treatments/guide/leprosy-symptoms-treatments-history#1>

<https://en.wikipedia.org/wiki/Leprosy>

Appendix 4: Guidance on impact of leprosy on psychological and emotional wellbeing

Introduction:

The visible signs of leprosy, notably physical disabilities and skin problems, can easily mask the impact leprosy has on people's mental, emotional and psychological health. While the physical impacts of *Mycobacterium Leprae* can be controlled and cured through Multi-Drug Therapy (MDT), its psychological impacts can last a lifetime, if they are not also recognised and treated appropriately. Health workers, social workers and academics are increasingly recognising that physical health; social inclusion and participation; and emotional and psychological health all depend on each other. Different words can be used to describe this relationship, but "well-being" sums them up. A person's Well-being can be thought of as a 3 legged stool. Although you can balance precariously on two legs for a short while, the stool can only really stand firmly on all three of its legs, which are: physical health, psychological and emotional health, and social inclusion/participation. For more detailed discussion on the middle leg of this stool, *The Leprosy Mission* is now promoting the term "Inner well-being", which refers to an individual's mental, emotional and spiritual state – how they are feeling, and how well they are able to cope with the stresses of their day-to-day life.

Several studies (Ref 2, 3, 4 & 5) suggest a link between leprosy and poor inner well-being, with people affected by leprosy far more likely than the general population to suffer from **depression** or **anxiety** in particular. Depression and Anxiety in turn can also lead to **alcohol** or **substance abuse**, although more research is needed on the links between leprosy and alcohol/substance abuse.

For example, studies conducted in India (Ref 2, 3, 4 & 5 link) show that up to two-thirds of leprosy patients also suffer from **depression**, which was higher among female patients than males, more likely among patients with visible disabilities and often most severe among patients suffering from E.N.L / Type 2 reaction. Women with leprosy were shown to be more prone to depression than men, as they are generally most likely to suffer isolation and rejection as a direct result of having leprosy. **Anxiety** on the other hand, was shown to be more common among male patients. Some leprosy patients suffer from a mixed depression and anxiety disorder.

What are depression and anxiety and what can be done to help those affected by them?

(Taken from "An Introduction to Mental Health: Facilitator's Manual for Training Community Health Workers in India", published by *Basic Needs & Nossal Institute*, Melbourne, 2009).

Depression can be understood as an unusually sad mood that does not go away.

In addition to this **unusually sad mood**, the following symptoms are also common with **depression**:

- Tiredness and lack of energy (Fatigue)
- Loss of self-confidence
- Feelings of hopelessness and helplessness
- Loss of interest and enjoyment in activities
- Difficulty concentrating
- Wishing they were dead
- Sleeping problems
- Loss of interest in food and loss of weight
- Experiencing a range of physical problems with no obvious cause – e.g. aches and pains.

Not everyone who is depressed has all these symptoms as depression affects different people in different ways.

Causes of Depression:

Depression is often caused by one or more factors which people feel are beyond their control, such as death of a loved one or breakdown of a relationship, conflict within the family or community, chronic medical conditions (including leprosy), and severe poverty or hardship. Also, women can sometimes become depressed for a time after giving birth (post-natal depression).

Anxiety means *excessive* fear, nervousness and worry (more severe and longer lasting than typical everyday worries), which interferes with someone's normal work and relationships. The **excessive fear** and **worry** of **anxiety**, are often accompanied by:

- Irritability (becoming easily annoyed by small things)
- Worrying about things a lot, even if they are only small things
- Feeling that something terrible is going to happen
- Feeling scared ("butterflies in the stomach" – which also affects appetite)
- Avoiding certain social situations, or meeting people
- Disturbed sleep
- Muscle tension
- Physical symptoms like restlessness/fidgeting, rapid heart-beat, dizziness and trembling.

Anxiety can be expressed through different **anxiety disorders**. These include: **Panic Disorder** when people experience sudden and severe anxiety attack and terror, often with dizziness, shaking, sweating and rapid breathing and heart beat; **Phobias** when a person feels very scared by particular situations or things (e.g. claustrophobia – fear of closed spaces, arachnophobia – fear of spiders); There are many other mental illnesses (sometimes referred to as "disorders") of varying complexity, and of course, it is possible that someone who contracts leprosy may already have been suffering from an underlying mental illness, which may increase under the pressure of coping with leprosy.

However, the high rates of depression and anxiety recorded amongst people affected by leprosy in India and elsewhere indicate that leprosy is a recognised cause of mental health difficulties. This might be directly through the **biological impact** of leprosy on the body - the skin lesions and ulcers, neuropathic pain, damage to eyes, feet and hands; or it might be through the **emotional or spiritual beliefs** which the patient may associate with the disease e.g. if someone believes that they have been cursed or are being punished for sins in a past life (whether their own, or someone else's), then this is highly likely to disturb their inner well-being. Whether or not these factors have directly affected the mental health of someone affected by leprosy, it is very likely that the **social impact** of leprosy on their life will do so. Marital break-up or separation from children/parents/siblings and friends is one of the biggest drivers of mental illnesses all over the world. The sadness of loneliness, bitterness of rejection and isolation, and possible feelings of low self-esteem or worthlessness associated with family breakdown and social exclusion can be devastating. When coupled with the **economic hardship and insecurity** caused by unemployment, expulsion from work/school and separation from family support structures, it should be no surprise that so many people affected by leprosy also suffer from depression and/or anxiety, whether for short or prolonged periods.

What can be done to address depression and anxiety?

The good news is that all of these problems can be addressed. The first step is to recognise them!

The second step is to promote an understanding and knowledge about leprosy and the ways in which it can affect people, not only physically but also mentally, emotionally, socially and economically. The best way to raise awareness is for people who have leprosy to have the opportunity to meet and interact with other people who have, or have been affected by, leprosy, e.g. by inviting people to join Self-Care and Self-Help Groups and other inclusive activities and/or to

meet a Counsellor. This does NOT mean banishing them to live in separate leprosy “colonies” or communities, excluded from the rest of society.

People leading self-help and self-care groups should be aware of the level of shock which someone experiencing leprosy may be feeling, especially when they are first diagnosed. It will not be helpful to sit them down and tell them that they have a disease which could also break up their home, shatter their self-esteem, ruin their livelihood/ career and cause them depression, —not least because it doesn’t have to be true. However, providing a warm welcome and a listening ear for someone learning to accept their leprosy diagnosis and helping them explore this in a safe and supportive environment can be of great value. People should never be lied to, but it is also important to offer hope and encouragement, rather than worsen their fears with a whole list of problems they may face. These opportunities to ask questions, to listen, share and build new relationships are difficult to enforce, but can occur naturally through shared practical activities like:

- Learning physical self-care including foot cleaning and ulcer care (Self-Care Group),
- Learning a new trade or vocational skill in a group,
- Participating in a group savings and credit scheme, (Self-Help Group)
- Joining an advocacy/human rights group,
- Enjoying a shared activity like tending a garden,
- Preparing and eating a communal meal.
- Attending a place of worship, or singing/dancing together.

Just as the causes of mental illnesses are inseparable from other aspects of our lives – physical, social, economic, spiritual, cultural and political; so should the solutions also be interwoven into these other aspects of life. Again, think of the three legs which make the stool stand firmly.

Having said that, people are complex and our minds operate at many different levels. While it may be beneficial for someone affected by leprosy to enjoy participating in a shared social, cultural or economic activity with other people, these benefits might only last for as long as the shared activity does, if there is no effort alongside this to dig a bit deeper into the underlying trouble. Also leaders should be aware that some people are naturally more or less sociable than others and that they may not always want to take part in such activities, especially if they have not yet developed trust and confidence in the other group members.

One of the best ways to do this is through **counselling**. But what is counselling?

Counselling is NOT simply giving advice. Counselling involves listening. Counselling is about supporting the person and empowering them to find their own solutions.

There are different forms of counselling: some people go to a professional mental health nurse or psychiatrist, some meet a Priest/Pastor or other religious leader, some get counselling from someone who has experienced the same problem they are facing (often called **Peer Counselling**), and some counsel each other in groups. Whatever method of counselling is used, the principles are usually the same:

(Adapted from “Basic Counselling Skills a Guide for health workers in maternal care”, Perinatal Mental Health Project, University of Cape Town, South Africa,)

The process of counselling involves the following:

- **Opening:** Establishing a relationship/building trust (which includes confidentiality).
- **Listening:** Really attentive listening encourages the exploration of the problem(s).
- **Responding:** The counsellor may clarify or reflect upon the problems to summarise them, and confirm they have understood correctly.

- **Deciding on intervention:** Understanding the situation the person is in, to help them identify the different parts of the problem and start finding some solutions. (Decision Making).
- **Helping the person plan** their own solutions
- **Monitoring and maximising resilience**– counselling shouldn't stop when decisions are made, following them through could be very difficult and may introduce new problems. The counsellor should keep offering encouragement through this long process.

What can counselling provide for someone affected by leprosy?

- A safe space to be heard – the person tells their whole story without fear of stigma or prejudice.
- A way to understand their own distress and its causes.
- Someone who will listen without blaming or judging them.
- Respect and self-confidence.
- Validation of their feelings.
- Help to develop a sense of dignity, value and of self-worth
- An opportunity to explore practical options and solutions.
- Support and solidarity.

Counselling is a process not a quick fix.

Sometimes counselling can help a person to identify, understand and come to terms with the problems they are facing, to see that they are not alone in facing these challenges and to identify potential solutions and develop the confidence to try them out.

At other times, counselling may uncover deeper and more complex problems which cannot be solved by the person(s) involved and cannot be ignored either. In such cases, the counsellor needs to be careful not to cause more harm than good and should seek professional help for the person by referring them for specialist mental health services, or other appropriate support services. People suffering from alcohol / substance abuse (or other addictions) usually need specialist help, both to help them deal with their addiction and to help them address the underlying problem(s) behind it.

Improving mental health and inner well-being is an important aspect of helping people affected by leprosy to heal, regain their dignity and transform their lives. These few pages serve only as an introduction to this topic. CSOs working for and with people affected by leprosy are encouraged to include well-being in their work plans and consider developing peer counselling within their activities. However, effective counselling requires further learning and training, and there are several ways of doing this within India, which don't need to cost money.

Please Note:

The following are recommended, either to read or contact directly for support and guidance:

<https://www.leprosy-information.org/resource/guidelines-reduce-stigma-guide-4-counselling-reduce-stigma>

Which you can download as a PDF, here:

https://www.leprosy-information.org/files/ILEP%20Stigma_guidelines_4%20Counselling%20to%20reduce%20stigma_0.pdf

Also, several good resources here, in both English and Hindi:

<http://projectburans.wixsite.com/burans/resources>

- *An Introduction to Mental Health: Facilitator's Manual for Training Community Health Workers in India*, published by Basic Needs & Nossal Institute, Melbourne, 2009 (also available in both Hindi & English): <http://projectburans.wixsite.com/burans/manuals>

- *Basic Counselling Skills: a Guide for health workers in maternal care*, Perinatal Mental Health Project, University of Cape Town, South Africa. 2010. Available to download here: <http://www.mhinnovation.net/sites/default/files/downloads/resource/PMHP%20Basic%20Counselling%20Skills.pdf>
- *Different. Just like you. A psychosocial approach promoting the inclusion of persons with disabilities*. International Federation of Red Cross and Red Crescent Societies, LICHT FÜR DIE WELT/Light for the World(Austria), International Council of Sport Science and Physical Education, JuulJournalistikogKommunikation/Tina Juul Rasmussen, 2015.
- *Wellbeing and Quality of Life Assessment:A Practical Guide*, Practical Action Publishing: UK, 2014 p.3-13.
- Ted Talk by Vikram Patel on Global Mental Health https://www.ted.com/talks/vikram_patel_mental_health_for_all_by_involving_all
- mpGAP WHO http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/

These organisation implements mental health work across India and can be a good source of support especially if you need information about how/where to refer someone with a more serious mental illness: <http://www.basicneeds.org/where-we-work/india/>
www.sangath.com(this website also has downloadable PDFs on counselling, alcohol abuse and other topics).

Scientific Reading:

1. *Inclusion of people with psychosocial disability in low and middle income contexts: A literature and practice review*, H Fernandes& Stephanie Cantrill, Published by TEAR Australia, 2016.
2. *Psychosocial aspects of Hansen's disease(leprosy)*, G.P. Singh, *Indian Dermatology Online Journal*, 2012, 3(3); p.166-170.
3. *Effect of Rehabilitation on the prevalence of psychiatric morbidity among leprosy patients*, K.K Verma& Shiv Gautam, *Indian Journal of Psychiatry*, 1994, 36 (4), p183-186.
4. *A study of anxiety in patients with leprosy in the context of current integrated scenario*, A.K. Yaduvanshi, A Abraham, S. Jain, & S. Tomar, *Indian Journal of Health & Wellbeing*, 2015, 6(8), p. 784-788.
5. *A Study of psychological correlate in leprosy patients of Agra and Kanpur district*, A.K. Yaduvanshi, A Abraham, S. Jain, & S. Tomar, *Indian Journal of Health & Wellbeing*, 2016, 7(3), p319-322.

Further resources and contacts on mental health can be found here: <http://www.mhinnovation.net/>;
 especially on their resources page: <http://www.mhinnovation.net/resources>

Appendix 5: Human Rights, Laws and Entitlements of People Affected by Leprosy

Appendix 5(A): Human Rights

What are Human Rights?

Human rights are rights inherent to all human beings, whatever our nationality, place of residence, gender, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

Human rights are the foundation of freedom, justice and peace. Respecting the human rights allows the individual and the community to fully develop.

The development of human rights has its roots in the struggle for freedom and equality everywhere in the world. The basis of human rights – such as respect for human life and human dignity – can be found in most religions and philosophies.

Characteristics of Human Rights:

Human rights do not have to be bought, earned or inherited, they belong to people simply because they are human – human rights are ‘inherent’ to each individual.

Human rights are the same for all human beings regardless of race, gender, religion, political or other opinion, national or social origin. We are all born free and equal in dignity and rights – human rights are ‘universal’.

Human rights cannot be taken away; no one has the right to deprive another person of his/her rights for any reason. People still have human rights even when the laws of their countries do not recognize them, or when they violate them - for example, when slavery is practised, slaves still have rights even though these rights are being violated – human rights are ‘inalienable’.

People have the right to live with dignity; all human beings are entitled to freedom, security and decent standards of living – human rights are ‘indivisible’.

Born out of the atrocities and enormous loss of life during World War II, the United Nations Universal Declaration of Human Rights (UDHR) was signed in 1948, to provide a common understanding of what everyone’s rights are. It contains 30 articles (sections) protecting civil and political rights; economic, social and cultural rights, and fundamental freedoms.

Some important Human Rights to remember:

1. **We Are All Born Free & Equal.** We are all born free. We all have our own thoughts and ideas. We should all be treated in the same way.
2. **Don’t Discriminate.** These rights belong to everybody, whatever our differences.
3. **The Right to Life.** We all have the right to life, and to live in freedom and with safety.
4. **No Torture.** Nobody has any right to hurt us or to torture us.
5. **We’re All Equal Before the Law.** The law is the same for everyone. It must treat us all fairly.
6. **Your Human Rights Are Protected by Law.** We can all ask for the law to help us when we are not treated fairly.
7. **The Right to Privacy.** Nobody should try to harm our good name. Nobody has the right to come into our home, open our letters, or bother us or our family without a good reason.

8. **Freedom to Move.** We all have the right to go where we want in our own country and to travel as we wish.
9. **Marriage and Family.** All grown-up people have the right to marry and have a family if they want to. Men and women have the same rights when they are married, and also when they are separated.
10. **The Right to Your Own Things.** Everyone has the right to own things or share them. Nobody should take our things from us without a good reason.
11. **The Right to Public Assembly.** We all have the right to meet our friends and to work together in peace to defend our rights. Nobody can make us join a group if we don't want to.
12. **The Right to Democracy.** We all have the right to take part in the government of our country. All grown-up people should be allowed to choose their own leaders.
13. **Social Security.** We all have the right to affordable housing, medicine, education, and childcare, enough money to live on and medical help, if we are ill or old.
14. **Workers' Rights.** All grown-up people have the right to work, to fair wages for their work, and to join any trade union of their liking.
15. **The Right to Play.** We all have the right to rest from work and to relax.
16. **Food and Shelter for All.** We all have the right to a good life. Mothers and children, people who are old, unemployed or disabled, and all people have the right to be cared for.
17. **The Right to Education.** Education is a right. Primary school education should be free. Our parents can choose where we are educated.
18. **Responsibility.** We have a duty to other people, and we should protect their rights and freedoms. **No One Can Take Away Your Human Rights.** As human beings, we are entitled to our rights. No person or higher authorities can restrict them.

Please Note:

For more information please see the below link

(Sources: www.hrea.org and www.youthforhumanrights.org)

Appendix 5(B): Rights guaranteed under the Indian Constitution

What are Fundamental Rights?

Fundamental Rights is a charter of rights contained in the Constitution of India. It guarantees civil liberties such that all Indians can lead their lives in peace and harmony as citizens of India. The Fundamental Rights are defined as basic human freedoms that every Indian citizen has the right to enjoy for a proper and harmonious development of personality. These rights universally apply to all citizens, irrespective of race, place of birth, religion, caste or gender. Violation of these rights result in punishments as prescribed in the Indian Penal Code or other special laws, subject to discretion of the judiciary. The six fundamental rights recognized by the Indian constitution are:

1. **Right to equality:** Which includes equality before law, prohibition of discrimination on grounds of religion, race, caste, gender or place of birth, and equality of opportunity in matters of employment, abolition of untouchability and abolition of titles.
2. **Right to freedom:** Which includes freedom of speech and expression, assembly, association or union or cooperatives, movement, residence, and right to practice any profession or occupation (some of these rights are subject to security of the State, friendly relations with foreign countries, public order, decency or morality), right to life and liberty, protection in respect to conviction in offences and protection against arrest and detention in certain cases.
3. **Right against exploitation:** Which prohibits all forms of forced labour, child labour and traffic of human beings.
4. **Right to freedom of religion:** Which includes freedom of conscience and free profession, practice, and propagation of religion, freedom to manage religious affairs, freedom from certain taxes and freedom from religious instructions in certain educational institutes.
5. **Cultural and Educational rights:** Preserve the right of any section of citizens to conserve their culture, language or script, and right of minorities to establish and administer educational institutions of their choice.
6. **Right to constitutional remedies:** Which is present for enforcement of Fundamental Rights.

Please Note:

For more information see the link below

https://en.wikipedia.org/wiki/Fundamental_rights_in_India

<http://www.nios.ac.in/media/documents/SecSocSciCour/English/Lesson-16.pdf>

Appendix 5(C): United Nations Convention on the Rights of Persons with Disabilities and Rights of Persons with Disabilities (RPD Act 2016)

What is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)?

UNCRPD is a resolution passed by the United Nations. The Convention is thus an international legal agreement which confirms that people with disabilities have the same human rights as everyone else. It details out the various measures and affirmative actions that various countries should undertake so that human rights become a reality for people with disabilities. This convention has been ratified by India. The principles of the UNCRPD are:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The UNCRPD gives special emphasis to:

1. Women with disabilities by stating that:

- States Parties recognize that women and girls with disabilities are subjected to multiple discriminations, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
- States parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the Convention.

2. Children with disabilities by stating that:

- States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
- States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

3. Awareness-raising by stating that:

- States Parties undertake to adopt immediate, effective and appropriate measures:
 - To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
 - To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
 - To promote awareness of the capabilities and contributions of persons with disabilities.

What is the Rights of Persons with Disabilities (RPD) Act 2016?

India has ratified the UNCRPD and is thus committed to ensure that measures and affirmative actions are in place in accordance to the UNCRPD. After almost a decade's wait, the Rights of Persons with Disabilities Act, 2016 was passed by Rajya Sabha on 14 December, 2016 and by Indian Parliament on 16th December 2016. The Government gazette notification was done on 28th December 2016. This RPD Act will replace the Persons with Disability (PWD) Act of 1995.

Salient features of the Act:

1. Reservation in vacancies in government establishments has been increased from 3% to 4% for certain persons or class of persons with benchmark disability.
2. Every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education.
3. District level committees will be constituted by the State Governments to address local concerns of PwDs.
4. Special Courts will be designated in each district to handle cases concerning violation of rights of PwDs.
5. Broad-based Central & State Advisory Boards on Disability are to be set up to serve as apex policy-making bodies at the Central and State level.
6. Office of Chief Commissioner and those of the State Commissioners of Persons with Disabilities has been strengthened.

The Act says that any person who "intentionally insults or intimidates with intent to humiliate a person with a disability in any place within public view" is punishable with imprisonment.

Please Note:

For More Information please see the link Below

<http://disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

Appendix 5(D): United Nations' Resolution No. A/HRC /15/30**Principles and Guidelines and Guidelines for Elimination of Discrimination against People against People Affected by Leprosy their Family Members**

Millions of people who once had leprosy continue to suffer from discrimination in education, employment, marriage and other aspects of their lives, due to strong stigma attached to the disease. Seeing the seriousness of the problem, United Nations Human Rights Council unanimously passed a resolution (Resolution 8/13) **A/HRC /15/30**, and India is one of the signatory, to end discrimination against people affected by leprosy and their family members.

The resolution:

1. Reminds governments that all persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedom detailed in international law, conventions, constitutions and laws.
2. Asks all governments to take effective measures to eliminate all forms of discrimination against people affected by leprosy and their family members.

The main Principles are:

1. Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms. Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.
2. Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood.
3. Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.
4. Persons affected by leprosy and their family members should have the right to serve the public, on an equal basis with others, including the right to stand for elections and to hold office at all levels of government.
5. Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated on an equal basis with others in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.
6. Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.
7. Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth.
8. Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

The major Guidelines set forth in the resolution are to ensure that States promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy. To this end, States should:

1. Take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination;
2. Ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.

The guidelines also assist the State in working towards:

1. Promoting equality and non-discrimination
2. Focussing on the development of women, children and other vulnerable groups
3. Encouraging a home and family life
4. Living in the community and housing
5. Participating in political life
6. Undertaking an occupation according to skills and choice
7. Promoting Education
8. Stopping discriminatory language
9. Participating in public, cultural and recreational activities
10. Accessing appropriate Health care
11. Ensuring adequate Standard of living
12. Raising awareness on leprosy to promote early detection and reduce stigma and discrimination

Appendix 5(E): Report No. 256 on 'Eliminating Discrimination against Persons Affected by Leprosy'

What is Report 256 and EDPAL Bill?

Report 256 is a detailed report put together by Law Commission (with support from TLMTI) that highlights stigma and discrimination faced by people affected by leprosy across India, It also consists of a draft bill entitled 'Eliminating Discrimination Against Persons Affected by Leprosy Bill, 2015' (EDPAL draft bill), which is still waiting to be taken through the law-making process. EDPAL firstly addresses the legal provisions in existing laws that have direct or indirect discriminatory effect on people on the grounds of leprosy. And secondly, the need for affirmative action not only for people affected by leprosy but also their family members who suffer the effects of the stigma associated with leprosy.

The Bill has built in provisions for protection from discrimination in all facets of human life from i) inclusion in society to ii) education, iii) employment, iv) healthcare, v) use of goods and services, and vi) ownership rights and vii) freedom of movement. The Bill also addresses the use of derogatory terms like 'Leper' and specifies its removal from all official usage. Then it goes on to cover a range of affirmative provision including education, health, employment, social security, movement, land ownership in leprosy colonies, awareness generation. EDPAL Bill also addresses the issue of definition of persons affected by leprosy vis-a-vis the current definition under the PwDs Act, 1995.

What are the discriminatory provisions that are not favourable for people affected by leprosy?

The Law Commission report identifies and demands a repeal of the following Indian laws as having either direct or indirect discriminatory provisions against persons affected by leprosy:

Type of discrimination	Laws	Provision Explained
Political participation	Multiple State municipal and panchayati Raj Acts such as in Andhra Pradesh, Delhi, Orissa.	Leprosy is a ground for refusing a person to stand for elections under these laws.
Divorce	All laws governing marriage and divorce issues such as Hindu Marriage Act, Special Marriage Act.	Having a virulent and contagious form of leprosy for a period of two or three years is a ground for divorce.
Separation	Hindu Adoption and Maintenance Act	Leprosy is a ground for refusal to pay maintenance during separation.
Beggary as a crime	Multiple State beggary acts as applicable in States like Delhi, Maharashtra, Andhra Pradesh etc.	Provide for punishment for persons arrested for begging and provide for higher punishments if caught the next time.
Restriction on movement	Multiple laws classify leprosy as a contagious and dangerous disease such as the Railway Act, Cantonments Act.	Based on this classification, States of India restrict and prohibit movement in certain areas, public spaces and markets.
Employment	The Industrial Disputes Act	The provision for termination on the grounds of continued ill-health has the potential of being misused.
Insurance	Life Insurance Act	Charge of a higher premium on the grounds of disability.
Definition of person cured of leprosy	Persons with Disabilities Act	Discriminatory in effect as it leaves out certain categories of people affected by leprosy from its ambit altogether.

What are the highlights of the proposed EDPAL Bill?

The highlights of the proposed Bill are:

- Its application to the whole of India, which means including the State of J&K.
- New term for defining person affected by Leprosy – ‘Disability due to Leprosy’ using the grade I & II definition without measurable parameters of extent of disability, as given in the disability laws.
- Altering the definition of Leprosy Cured under the present Disability law to include anyone who has been administered the first dose of MDT, thus widening the scope. It further removes the 40% measurable criteria for this category of disability.
- Introduces the term ‘Person affected by Leprosy’ to include those still untreated to those cured.
- Broadens the definition of family member of person affected by leprosy to include parents, spouse, children and siblings.
- Provision of non-discrimination and equality applicable to both persons affected by leprosy and their family members.
- Provision of non-discrimination and equality applicable against all including individuals, any establishment and government.
- Providing precise schedules for repealment, invalidation and amended in one stroke – as per the schedules.
- Substitution of term ‘leper’ with ‘person affected by leprosy’.
- Increasing the ambit of healthcare from just care and treatment of leprosy and its consequences.
- Protection from disclosure of medical records pertaining to status of leprosy.
- Broad rights of ownership, occupation and enjoyment of facilities extended to family members as well.
- Broad protection of the right to movement and obtaining of driving license.
- All affirmative rights formed in a broad sweeping language and extending to family members as well including rights such as education, training, employment, holding public office and right to form a family including marriage and adoption.
- Affirmative actions clauses without the rider of State’s convenience but in a more mandatory nature of doing.
- Affirmative actions for healthcare looking at the broad issues of discrimination in healthcare, awareness generation of early detection and treatment, highest attainable standard of healthcare, proper training of health-workers and counselling.
- Emphasising on title of lands in colonies also provides protection from eviction without due process of law, rehabilitation arrangements and compensation.

- Social welfare schemes to range from financial support with emphasis on poverty reduction, insurance, social security, community based rehabilitation and support factors for addressing discrimination.
- Addressing educational and training needs by focusing on developing capabilities and full potential of the individual.
- Special focus on awareness raising to dispel stigma and misconceptions surrounding leprosy.
- Promoting a participatory approach in the formation of policies and programmes under the said legislation.
- Formation of a separate Commission body to ensure implementation of this Act, at both Central and State levels in the form of Commissions on Leprosy. TO be done within 12 months of the coming into force of the Bill.
- Provision to move the district courts for non-compliance of the provisions of the legislation against both private and public parties, with compensation figure at Rs. 25,000/- excluding litigation expenses.
- The Bill to be in addition to the disability laws in the country but to its extent to have over-riding effect on other laws.

Please Note:

For More information please see the link below

<http://lawcommissionofindia.nic.in/reports/Report256.pdf>

<http://pib.nic.in/newsite/PrintRelease.aspx?relid=118021>

Appendix 6: Tips on working with the media to publicise leprosy-related stories

Remember:

1. Methods of communication selected and messages given should be compatible with prevailing social or religious norms in the place where the communication activity is carried out.
2. Activities should respect the local environment.
3. In all communication activities, the local language(s) should be used as far as possible.

In order to maximize the impact of engaging the media:

1. Activities need to be timely
2. Information used must be accurate
3. The right audience(s) should be targeted
4. Messages should interest the target audience(s)

Some ways of working with media include but not limited to press releases, press visits, and publications. Tips on using these are provided below

Press releases

- Press releases can be a very useful way of disseminating information about the CREATE project.
- A newsworthy press release should contain: a heading, a strong leading paragraph summarising the essential facts, the main body of the story, quotes, some background information, and contact details for further information.

Press Visits

- Group visits by journalists to CREATE project areas may offer additional visibility opportunities.
- Such visits should be well-timed and focus on tangible achievements.

Publications

- Publications such as leaflets, brochures can be useful in communicating the work or its impact to specific audiences.
- Leaflets and Brochures should provide basic factual information and the address (such as a mailing address or web site) where further information can be found;
- Publications should always be tailored to the audience in question, and focus on the intended impact.
- Texts should be short and simple, and photographs used where possible to illustrate the work and its context.

Remember that the media is a powerful means of making your work known to many and soliciting support for the cause. Use the media effectively to complement your efforts at the field.

Appendix 7: Guidance for accessing government welfare schemes in India

Rights of Persons with Disabilities Act, 2016

This Act replaces the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. It fulfills the obligations to the United National Convention on the Rights of Persons with Disabilities (UNCRPD), to which India is a signatory. The Act came into force during December 2016.

Disabilities covered

1. Disability has been defined based on an evolving and dynamic concept.
2. The types of disabilities have been increased from existing 7 to 21 and the Central Government will have the power to add more types of disabilities. The 21 disabilities are given below:-
 1. Blindness
 2. Low-vision
 3. Leprosy Cured persons
 4. Hearing Impairment (deaf and hard of hearing)
 5. Locomotor Disability
 6. Dwarfism
 7. Intellectual Disability
 8. Mental Illness
 9. Autism Spectrum Disorder
 10. Cerebral Palsy
 11. Muscular Dystrophy
 12. Chronic Neurological conditions
 13. Specific Learning Disabilities
 14. Multiple Sclerosis
 15. Speech and Language disability
 16. Thalassemia
 17. Hemophilia
 18. Sickle Cell disease
 19. Multiple Disabilities including deaf blindness
 20. Acid Attack victim
 21. Parkinson's disease
3. Persons with "benchmark disabilities" are defined as those certified to have at least 40 per cent of the disabilities specified above.

Rights and entitlements

- Responsibility has been cast upon the appropriate governments to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others.
- Additional benefits such as reservation in higher education (not less than 5%), government jobs (not less than 4 %), reservation in allocation of land, poverty alleviation schemes (5% allotment) etc. have been provided for persons with benchmark disabilities and those with high support needs.
- Every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education.

- Government funded educational institutions as well as the government recognized institutions will have to provide inclusive education to the children with disabilities.
- For strengthening the Prime Minister's Accessible India Campaign, stress has been given to ensure accessibility in public buildings (both Government and private) in a prescribed time-frame.

Guardianship

- The Act provides for grant of guardianship by District Court under which there will be joint decision – making between the guardian and the persons with disabilities.

Establishment of Authorities

- Broad based Central & State Advisory Boards on Disability are to be set up to serve as apex policy making bodies at the Central and State level.
- Office of Chief Commissioner of Persons with Disabilities has been strengthened who will now be assisted by 2 Commissioners and an Advisory Committee comprising of not more than 11 members drawn from experts in various disabilities.
- Similarly, the office of State Commissioners of Disabilities has been strengthened who will be assisted by an Advisory Committee comprising of not more than 5 members drawn from experts in various disabilities.
- The Chief Commissioner for Persons with Disabilities and the State Commissioners will act as regulatory bodies and Grievance Redressal agencies and also monitor implementation of the Act.
- District level committees will be constituted by the State Governments to address local concerns of PwDs. Details of their constitution and the functions of such committees would be prescribed by the State Governments in the rules.
- Creation of National and State Fund will be created to provide financial support to the persons with disabilities. The existing National Fund for Persons with Disabilities and the Trust Fund for Empowerment of Persons with Disabilities will be subsumed with the National Fund.

Penalties for offences

- The Act provides for penalties for offences committed against persons with disabilities and also violation of the provisions of the new law.
- Any person who violates provisions of the Act, or any rule or regulation made under it, shall be punishable with imprisonment up to six months and/ or a fine of Rs 10,000, or both. For any subsequent violation, imprisonment of up to two years and/or a fine of Rs 50,000 to Rs five lakh can be awarded.
- Whoever intentionally insults or intimidates a person with disability, or sexually exploits a woman or child with disability, shall be punishable with imprisonment between six months to five years and fine.
- Special Courts will be designated in each district to handle cases concerning violation of rights of PwDs

ISSUE OF DISABILITY CERTIFICATES, NATIONAL IDENTITY CARDS AND PASS BOOKS

(a) PROCEDURE FOR OBTAINING A DISABILITY CERTIFICATE

The differently-abled persons are provided with various types of assistance based on their disability and age. For this purpose, all the persons with disability are provided Identity cards and with disability certificate. Doctors working in Government Hospitals, Government Primary Health Centres, Government Institutions and Local Hospitals are encouraged to issue disability certificate to the eligible disabled persons.

Medical bodies authorized to issue different types of disability certificates are as follows:

S/№	Type of disability	Medical Authority: For issuing disability certificates	Person to issue certificate of disability
1	Locomotor disability due to amputation or complete permanent paralysis of limbs	Hospitals/Institutions/Primary Health Centres run by Government/Local bodies.	Any medical practitioner working in Hospitals/ Institutions/ Primary Health Centres run by Government and Local Bodies
2	Multiple Disability	District Hospital/ Other Hospitals/ Institutions run by the State Government or Local Bodies having relevant medical specialist and testing facilities	Medical Board consisting of three members of whom one will be a specialist dealing with the relevant disabilities
3	Disabilities not Mentioned at Serial number 1& 2 above	Hospitals/ Primary Health Centres/Institutions run by Government/ Local Bodies	A specialist dealing with the relevant disability as specified in the table given below:

Specialists who can issue certificates to persons with disabilities mentioned above are:

S/№	Category of Disabilities	Specialist
1	Cerebral Palsy	Physical Medicine and Rehabilitation or Orthopaedics or Paediatrician or Paediatric Neurologist or Psychiatrist
2	Hearing Impairment	Specialist in the field of E.N.T
3	Leprosy cured person	Physical Medicine and Rehabilitation or Orthopaedics or Dermatologist
4	Locomotor disability other Than amputation of complete permanent paralysis of limbs	Physical Medicine and Rehabilitation of Orthopaedics.
5	Mental illness	Psychiatrist
6	Mental Retardation	Children with mental retardation below the age of 12 years. Paediatrician or Paediatric Neurologist or Psychiatrist For adults, above the age group of 12 years- Psychiatrist.
7	Low Vision / Blindness	Specialist in the field of Ophthalmology.
8	Autism	Psychiatrist or Pediatrician or Neurologist

(b) ISSUE OF NATIONAL IDENTITY CARD AND PASS BOOK

Those who have disability certificate with 40% disability and above may approach the respective District Differently Aabled Welfare Officer for registration. S/he in turn will register and issue a National Identity Card with a pass book after affixing seal in the family card. Those differently abled persons, who have obtained National Identity Cards can register as members in the State Welfare Board for the differently abled persons and avail benefits under various social security and welfare schemes of the Welfare Board.

SPECIAL EDUCATION ASSISTANCE FOR DIFFERENTLY ABLED STUDENTS TO FACILITATE THEIR EDUCATION

The Government has been taking steps to ensure that the persons with disabilities are not excluded from the general education system. To achieve this goal, special education is being provided to the differently abled students studying in Government and Government Aided Special Schools across the State.

The students studying in the Government special schools are given boarding and lodging facilities free of cost. Sports materials, teaching learning materials and Solar water heaters and power laundry are also provided to these Special Schools. Students studying in these Government special schools are also taken out for educational study tour once in a year.

SCHOLARSHIP

The Government provides scholarship to the students depending on their level of education with the prime intention of motivating the students to pursue higher education.

READERS ALLOWANCE

In order to encourage the learning process for the visually impaired students, Government has been providing Readers' Allowance to the students from 9th Standard upto Post-Graduation level.

ENSURING EMPLOYMENT OPPORTUNITIES FOR THE DIFFERENTLY ABLED PERSONS THROUGH RESERVATION

The Government is committed to provide job opportunities to the differently abled persons by ensuring 3 percent job reservation for them in Government Departments/Government Undertakings and other Government Agencies. A Committee has been constituted under the Chairmanship of Chief Secretary to Government with Secretaries of various departments as members to oversee the implementation of 3 percent reservation in all Government Departments / Undertakings / Government Agencies.

Follow-up action is being taken on a regular basis. In the Education Department, with regard to teaching posts 2% vacancies are reserved for the visually impaired persons while 2% vacancies in nonteaching posts are reserved for the hearing impaired persons. 1% of vacancies in both teaching and nonteaching posts are reserved for the orthopedically handicapped.

MICRO ENTERPRISES AND BUNK STALLS

The differently abled persons who wish to go for self-employment ventures and micro enterprises (like setting up of bunk stall) are assisted in availing loans from the Nationalised Banks. A subsidy of Rs.10,000/- or one third of the loan amount, whichever is less, is also given to the differently abled persons, to install Bunk Stall in public places.

PRIME-MINISTER'S EMPLOYMENT GENERATION PROGRAMME

To provide opportunities of self-employment to the differently abled persons under Prime Minister's Employment Generation Scheme, 5% share amount to be paid by the differently abled persons as margin money is borne by the State Government as grant. To avail this concession, the differently abled persons submit applications to the District Differently Abled Welfare Offices, which are scrutinized and placed before the District Selection Committee headed by the District Collector for the selection of beneficiaries.

NHFDC ASSISTED SELF-EMPLOYMENT SCHEME

The National Handicapped Finance and Development Corporation (NHFDC) functions as an Apex institution for channelising the funds to persons with disabilities through the State Channelising Agencies (SCAs) nominated by the State Government(s).

NHFDC provides financial assistance for skill & entrepreneurial development to Enhance the Employbilty or Increased Opportunity of Self Employment of Persons with disabilities. Schemes of NHFDC are implemented through State Chennelising Agencies. Financial assistances are provided through Nationalised Banks and State Central Cooperative Banks. In order to encourage a large number of persons with disabilities to take up various economic(livelihood) activities and higher education for their economic development, Loan interest rates are kept very low. And to encourage women with disabilities further rebate of 1% on self employment loans and 0.5 % on educational loan is provided.

UNEMPLOYMENT ALLOWANCE TO THE DIFFERENTLY ABLED PERSONS

To take care of the wellbeing of the unemployed differently abled persons in the age group of 18-40 years, the state government is giving unemployment allowance based on their educational qualification. To avail the benefit under this scheme, the unemployed persons with disabilities should have been in the live register of employment exchange for a minimum period of one year.

MAINTENANCE ALLOWANCES

a) Maintenance Allowance to Mentally Retarded Persons, Severely Affected Persons and Persons Affected with Muscular Dystrophy

To ensure better care of the persons with disabilities, Government enhanced the monthly maintenance allowance has been enhanced

S/№	Category of Disability	Criteria:percentage of Disability	Income ceiling
1	Mentally Retarded persons	45% and Above	No
2	Severely Affected persons	75% and above	No
3	Persons Affected with Muscular Dystrophy	40% and above	No

Maintenance Allowance is provided by the Government through ECS to bank account of the individual beneficiary directly from the Treasury. Person with disability has to apply for availing this benefit through concerned revenue department in their respective states.

b) MAINTENANCE ALLOWANCE TO PERSONS AFFECTED BY LEPROSY

The persons affected by leprosy are also being given maintenance allowance in few of the Indian states. The residents of the Government Rehabilitation Homes are also eligible to receive this allowance. The allowance is being sent through "ECS" directly from Treasury to the bank account of the beneficiaries.

AIDS AND APPLIANCES TO THE PERSONS WITH DISABILITIES

The following aids and appliances are provided to the persons with disabilities based on their needs through the District Differently Abled Welfare Offices, to enable them to lead an independent life.

- (a) Tricycles,
- (b) Wheel chairs;
- (c) Goggles;
- (d) Folding sticks;
- (e) Braille Watches;
- (f) Hearing Aids;
- (g) Solar Rechargeable Batteries;
- (h) Callipers;
- (i) Crutches; and
- (j) Artificial limbs

Callipers and Artificial Limbs are designed, fabricated and fitted by orthotic technicians along with the leather workers for each and every individual as per their need at the units of District Differently Abled Welfare Offices.

II. MODULAR AIDS AND APPLIANCES

- (a) Modular Artificial Limbs
- (b) Reflecting Folding Sticks
- (c) Retro-fitted Petrol Scooters;
- (d) Behind the ear hearing aid;
- (e) Modified Cerebral Palsy Wheel Chairs for the persons affected by Cerebral Palsy.
- (f) Magnifier, and
- (g) Energy Storing Carbon Fibre Foot limb for Sports Persons.

(a) SUPPLY OF MODULAR ARTIFICIAL LIMBS FOR THE STUDENTS WITH DISABILITIES.

Artificial limbs are provided to the beneficiaries through the District Differently Abled Welfare Offices. The latest Modular Functional Artificial Limbs (Modular Transtibial Prosthesis/Modular Transfemoral/Modular Below-Elbow) are provided to the amputee individuals free of cost to facilitate their mobility.

TRAVEL CONCESSION TO THE PERSONS WITH DISABILITIES IN STATE-OWNED TRANSPORT CORPORATION BUSES

Travel concession is provided to the persons with disabilities in the State-owned Transport Corporation buses without any income ceiling, as detailed below:

The students with disabilities, studying in the special schools are permitted to travel free to and from their residence to special school. The Visually Impaired persons are permitted to travel without charges in the Government Transport Corporation buses up to 100Km from their residence without any condition. All other persons with disabilities are permitted to avail travel concession with certain conditions in order to pursue their education, visit hospitals, training centres and to undertake employment.

The Persons with Mental Retardation are permitted to travel along with one escort free of cost. All categories of persons with disabilities can avail 75% concession to travel to any place in the State in all types of buses except air-conditioned bus without any restriction on the number of trips. 75% concession is also given to the escorts who accompany the persons with disabilities who cannot travel alone.

MARRIAGE ASSISTANCE SCHEME

Marriage assistance schemes are being implemented with the objective to encourage normal persons to marry the person with disabilities.

CONCLUSION

The Government is committed to improving the quality of life of the persons with disabilities. Towards achieving this goal the Government would make continuous effort in preventing disability through various early intervention schemes and also promote social integration by ensuring equal opportunities.

Appendix 8: Welfare Schemes available across Four States, where CREATE Project is operational

S/No	Government Schemes	Andhra Pradesh	Chhattisgarh	Tamil Nadu	Uttar Pradesh
1	Reservations	Reservations	Reservations	Reservations	Reservations
		In Grade C & D posts VI-1%, OH-1%, HI-1%	3% reservation for disabled persons. Job for eighth class passed individuals	In Grade C & D posts VI-1%, OH-1%, HI-1%	3% reservation for VI-1%, OH-1%, HI-1%
A	In Government Jobs	Upper age limit 10 yrs extended for PWD	Upper age limit 10 yrs extended for PWD	Upper age limit 10 yrs extended for PWD	Upper age limit 10 yrs extended for PWD in Group C and D
					upper age limit 5 yrs extended for PWD in Group A & B
B	In Education	ITI (3%)	Eighth pass. Age limit 18-40 years	3% seat in educational institutions/training centres/ professional courses	Fee relaxation - agra,kanpur,Meerut Universities
		BED (3%)	50 % Concession in train fare	Except medicine	Reservation in admission to 5% Ruhelkhand university (in all central university)
		BE (3%)			
		MBBS (3%)			
C	In Fair price shop	Yes	Yes. 35 kilos rice @ Re.1/-, 10 kgs wheat @ Rs 9.25/-, 1kg sugar @ Rs. 13.50/-, 1 litre kerosene @ Rs. 9/-BPL		
D	Housing board	Yes			

S/No	Government Schemes	Andhra Pradesh	Chhattisgarh	Tamil Nadu	Uttar Pradesh
2	Scholarships/ stipends	OH/VI/HI			
		Amount in Rs per month	Amount in Rs per month	Amount in Rs per month	Amount in Rs per month
	I to V		50	500	15
	VI to VIII		60	1500	20
	IX,X and Intermediate		Day scholar- 70/85 Hostler- 140; Additional reader allowance for blind- 50	2000	85
	Degree, PG		Day scholar- 125 Hostler- 180; Additional reader allowance for blind- 75	3000	125
	Professional courses		Day scholar- 170 Hostler- 240; Additional reader allowance for blind- 100	3500	170
3	Disability pension	< 80% of Disability :Rs 1000/-, >80% of Disability Rs1500/-	Indira Gandhi National Pension YojanaRs 350/per month for age 18-59 years	1000	500
4	Unemployment allowance		Unemployment stipend Rs.1000/ per month for 1 year only for graduates; For Eighth pass- Rs 200/PM	For VI at an age group of 18 to 40 Years	
					UG/PG- Rs.450pm, HSC-Rs. 300 pm, SSLC- Rs.150pm

S/No	Government Schemes	Andhra Pradesh	Chhattisgarh	Tamil Nadu	Uttar Pradesh
5	Conveyance allowance	VI/OH 10% basic pay to maximum Rs. 175		Rs.1000 pm to all PWD working in State Govt.	State Govt employee up to Rs.999pm- Rs.30pm, for pay level 1000 to 1999pm- Rs 50pm, Pay level Rs.2000 above- Rs.60pm.
6	Bus concession	Free in City and in sub urban with escorts	Up to 80% concession but there is no State Road Transport Service in Chhattisgarh	Free bus transport for VI	100% discount on Gov't buses for disabled person (by showing their original PWD certificate). Person having disability more than 80% gets free bus travel concession for escort/helper
		50% concession		Free bus for MIR/MI with one escort	
				Free bus for HI/OH/LD given for school,college,work	
7	Economic assistance for Self-employment	Loan amount Rs.30,000 Subsidy and for ST&SC Rs40,000/- as grant.	Financial assistance provided for self-employment in Urban max Rs. 2 lakhs and in Rural 1.6 lakhs	Loan amount Rs.3000	20,000 for self-employment if he had his own place for shop and 10,000 if he take shop on rent
		Subsidy on loan 30%	<Rs.50,000 interest 5%, Rs. 50,000 to 5 lakhs interest 6%, >5 Lakhs interest 8%		
8	Concessions/ Grace time in exams	Grace time of 30 minutes is given to all VI up to secondary level	In rural areas, subsidy 50%, maximum of Rs. 5000/-		Only VI are given grace time, writer, relaxation in maths, science and geography
		HI exempted from language	Grace marks in exam 5%		
9	Incentive for marrying a disabled person	Rs.1,00,000 is offered to normal person marrying disabled	Rs. 21,000 is offered to normal person marrying a disabled person	Norma persons marrying VI will get	Rs. 15000 is given for normal persons marrying PWD and 20,000 if both are disable

S/No	Government Schemes	Andhra Pradesh	Chhattisgarh	Tamil Nadu	Uttar Pradesh
				Rs. 12,500 in the form of NSC	
				Rs. 12,500 in cash towards marriage expenses	
10	Exemption in professional tax	Complete blind and crippled person			
11	Assistance for purchase of Aids and appliances	Free for parents' income <Rs. 14,400 50% concession for parent income between Rs. 14,000 to Rs. 30,000	Free for parents' income < Rs.5000 50% for parents' income Rs. 5001-8000	Free Tricycles: OH/income <Rs.30,000 PA Free wheel chairs: LD/ income <Rs.30,000 PA	Free appliance at a cost of Rs. 1000 is given for PWD
				Free hearing aid: HI/income<Rs.12,000 PA	
				Free goggles and folding sticks for VI	
12	Awards / incentives		Best employee/PWD/Rs. 5001 and certificate Best Employer/PWD/Rs. 10,001 and certificate Best NGO/PWD/ Rs.5001 and certificate Best District/ one shield and certificate		Award for Best PWD Employees Award for best self-employment Award for best Placement officer
13	Maintenance allowance			Rs. 1000pm given to OH and MR having 75% disability	Rs. 225
14	Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA)		100 days' work for everyone if they can work. Minimum wages Rs 167/day		100 days employment per year, Paid at minimum wage as set, but at least Rs 156 per day, Suitable work is to be given to differently-abled people

S/No	Government Schemes	Andhra Pradesh	Chhattisgarh	Tamil Nadu	Uttar Pradesh
15	Train concessions	50%	15 % concession in Passenger trains from 18 years. 80% in Sleeper class, 50% in AC, 25% in Rajdhani		Orthopaedically & Blind & mental retardation: 75% for all classes except 50% in 2AC & 1AC and 25% in Rajdhani/Shatabdi)
					Auditory and speech impaired: 50% only for the disabled and carer
16	Indira AwaasYojana	10%			Mentally & physically challenged persons (with at least 40% disability
	AtalAwaasYojana	10%	Govt will provide Rs 60000/- for house construction to be completed within two years under the scheme		Rs70,000 (or Rs75,000 in hilly area) for construction of new house - 5 houses/year are reserved for PWD
					Rs15,000 for upgradation of kaccha house to pacca house
17	Person affected by leprosy pension	>40% Disability	Rs. 350/PM	Rs. 1000PM (40% disability)	Rs. 2500/PM
18	DeendayalNishaktPunarwasKaryakram		Issuing of certificate, identity-card and passbook for person having above 40 % disability so that they access government schemes		

Please Note:

For More Information please see the link below

<http://vikaspedia.in/social-welfare/differently-abled-welfare/rights-of-persons-with-disabilities-act-2016>

http://cms.tn.gov.in/sites/default/files/documents/wda_e_cc_2016_17.pdf

<http://www.eyeway.org/?q=andhra-pradesh-state-schemes-persons-disabilities-department-welfare-womenchildrendisabled-and>

<http://wcdsc.ap.nic.in/>

<http://www.eyeway.org/?q=uttar-pradesh-state-schemes-persons-disabilities-directorate-handicap-welfare-department>

<http://www.disabilityaffairs.gov.in/content/>

<http://www.commissionerdisabilitiesup.in/>

<http://www.eyeway.org/?q=chhatisgarh-state-schemes-persons-disabilities-social-welfare-department>

https://www.sightsaversindia.in/wp-content/uploads/2014/06/17581_Policies-and-Schemes-of-Central-and-State-Governments-for-People-with-Disabilities.pdf

Appendix 9:

Pictures to be used for module 1:

- A. Signs and symptoms of leprosy : Pale or reddish patches on skin



- B. Eye lids do not close properly if nerves in the eyes are damaged: Because eye muscles are weak



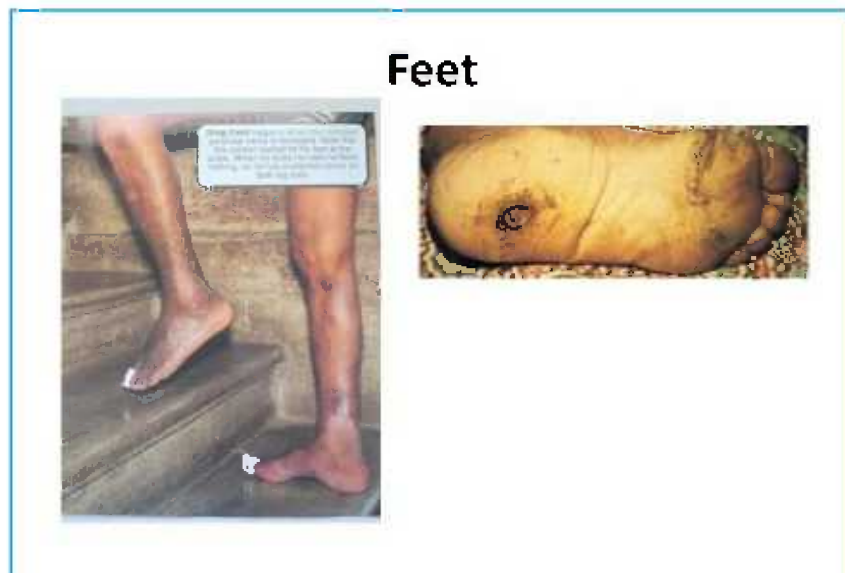
- C. Skin Smear testing



- D. Fingers become clawed if nerves in the hands are damaged; It is difficult to grip objects well because tendons in hands are damaged



- E. Foot Drop and ulcer in foot



Pictures on Diagnosis and treatment of leprosy:

Physical examination



Laboratory diagnosis



Leprosy Treatment

Multi-Drug Therapy

Drugs are supplied in packs that contain the correct dose for 1 person for 4 weeks.

It is available free of charge via the World Health Organization (WHO)



Picture cards used in modules

Picture cards or illustration (for Module 1):

Pictures should be printed on Cards of approx. 15cm x 10cm (or near equivalent), which can be laminated for repeated use.

Module 1, Exercise 1.2
<ol style="list-style-type: none">1. Living in same house / regular contact with an infected person.2. From the mucus of an infected person coughing3. Spread of leprosy from parent to child (heredity).4. Shaking hands or touching.5. Married life.6. Contact with ulcers.7. Washing / Bathing someone affected by leprosy.8. Bathing in the same pond, tank or river.9. Sharing cups or plates.10. Breastfeeding.11. Sharing bedsheets/towels/clothing.12. Buying food items from someone who has leprosy.13. Using the same toilets.14. Mosquito Bites.15. Going to the same barber / hairdresser.16. Going to Tea-shop17. Being cursed.18. Eating dried fish and drinking milk.

Picture cards to be used in the module 1:

Living in same house / regular contact with an infected person



From the mucus of an infected person coughing



Spread of leprosy from parent to child (heredity)



Shaking hands or touching



Married life



Contact with ulcers



Washing / Bathing someone affected by leprosy



Bathing in the same pond / tank



Sharing cups or plates



Breastfeeding



Sharing bedsheets/towels/clothing



Buying food items from someone who has leprosy



Using the same toilets



Mosquito Bites



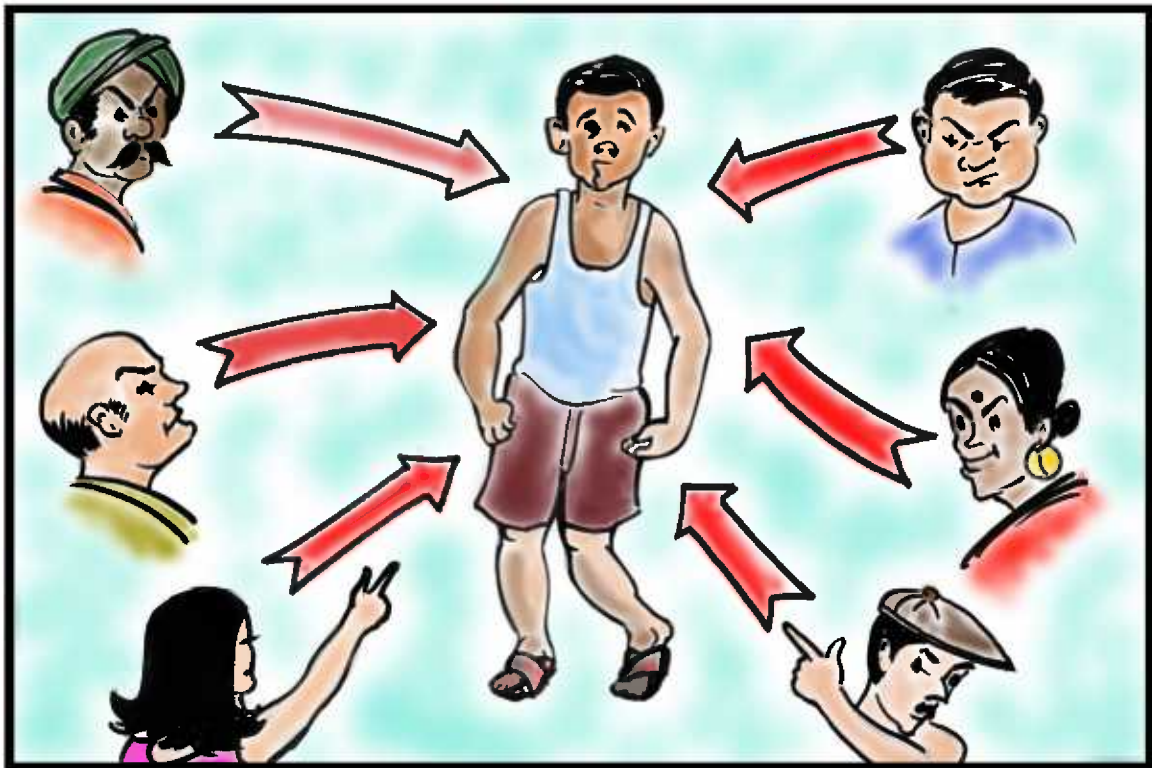
Going to the same barber / hairdresser



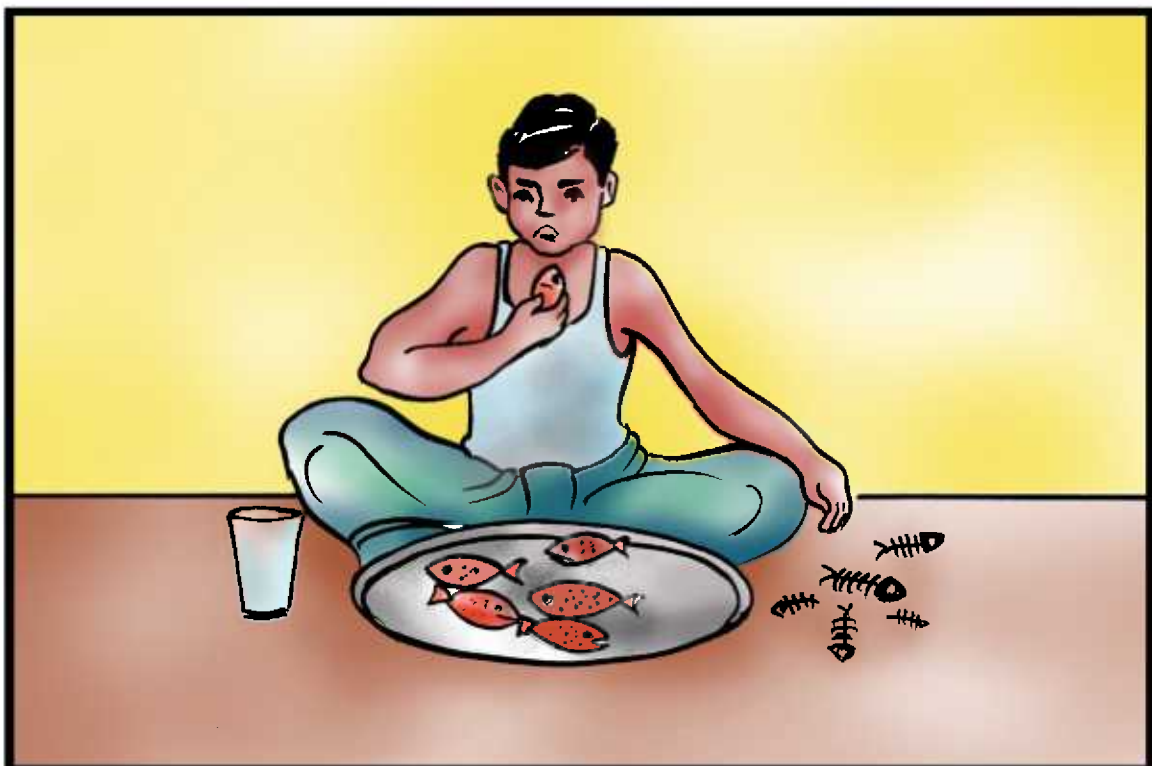
Going to tea-shop



Being cursed



Eating dried fish and drinking milk



Picture cards or illustration (for Module 2):

Description: These picture cards show scenes of stigma or discrimination as a starting point for discussion. These picture cards or illustrations can be used as single picture cards for a specific exercise or a full set of pictures used in the part of module 2, “Naming Stigma through Pictures”.

1. Community members point fingers at one man
2. Two women gossiping about another woman
3. Family thrown out of the rented house
4. Woman sitting alone, left out of family discussion
5. Worried man returns home with leprosy diagnosis results
6. Man being fired from his job
7. Stigma in hospital/clinic 1: Doctor and nurse gossiping about patient
8. Stigma in hospital/clinic 2: Nurse giving injection to patient from a distance
9. Stigma in hospital/clinic 3: Patients and nurse scared by seeing leprosy patient in hospital
10. Health worker refuses to visit sick man (suspected of having leprosy)
11. Isolation at playground : Three boys playing football; one boy is excluded
12. Excluded from social event : Community celebration; one woman is excluded
13. Stigmatized at the tea shop : Man arrives and customers stand up to leave
14. Rejected at the water point : Line of women at public tap; one woman rejected
15. Separated from the child : Woman prevented from holding her child

Community members point fingers at one man



Two women gossiping about another woman



Family thrown out of rented house



Woman sitting alone, left out of family discussion (decision making)



Worried man returns home with leprosy diagnosis results



Man being fired from his job



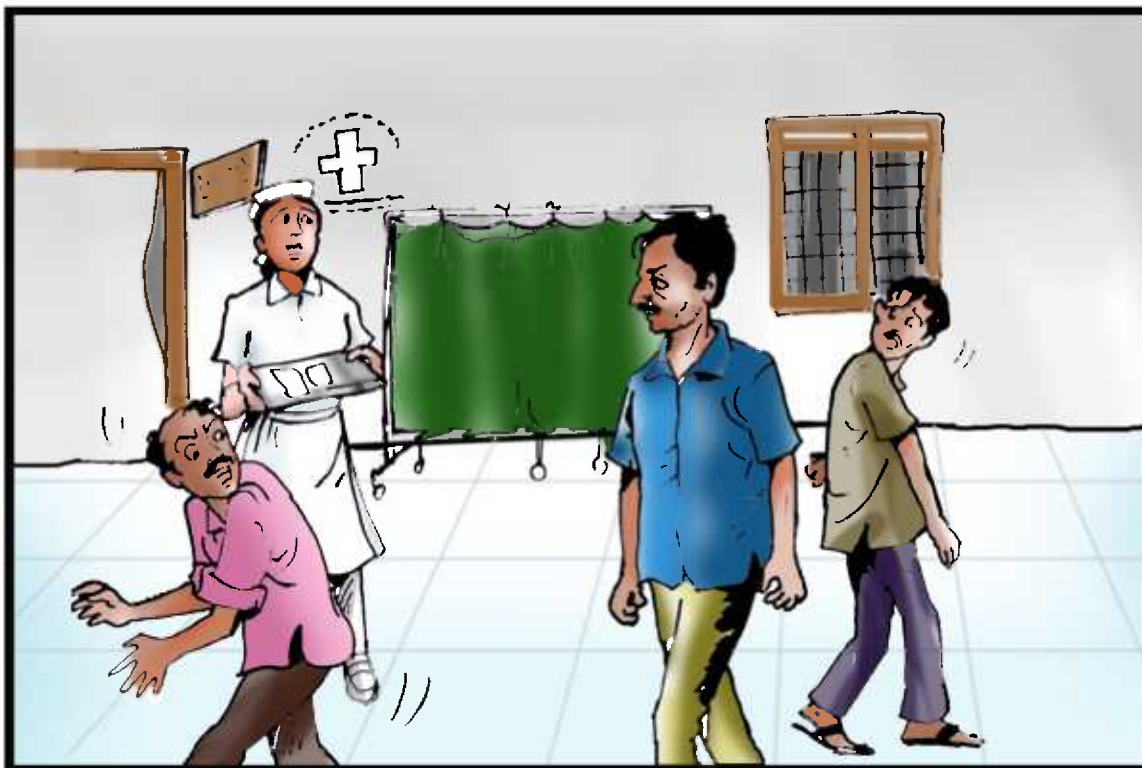
Doctor and nurse gossiping about patient



Nurse giving injection to patient from a distance



Patients and nurse scared by seeing leprosy patient in hospital



Health worker refuses to visit sick man (suspected of having leprosy)



Three boys playing football; one boy is excluded



Community celebration; one woman is excluded



Man arrives and customers stand up to leave



Line of women at public tap; one woman rejected



Woman prevented from holding her child

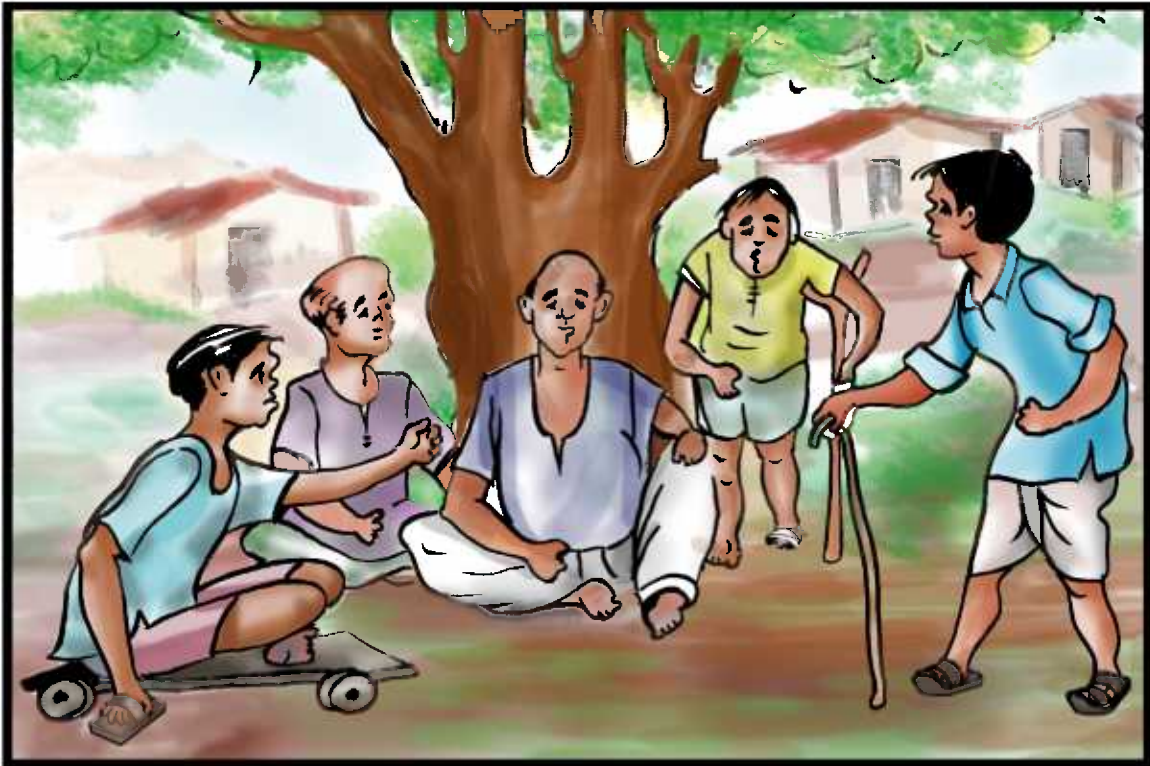


Picture cards to be used in the module 3:

Pictures should be printed on Cards of approx. 15cm x 10cm (or near equivalent), which can be laminated for repeated use.

Module 3, Exercise 3.2
1. People affected by leprosy
2. Beggars
3. People living with HIV/AIDS
4. Politicians
5. Police
6. People who are transgender
7. Sex Workers
8. Elderly People

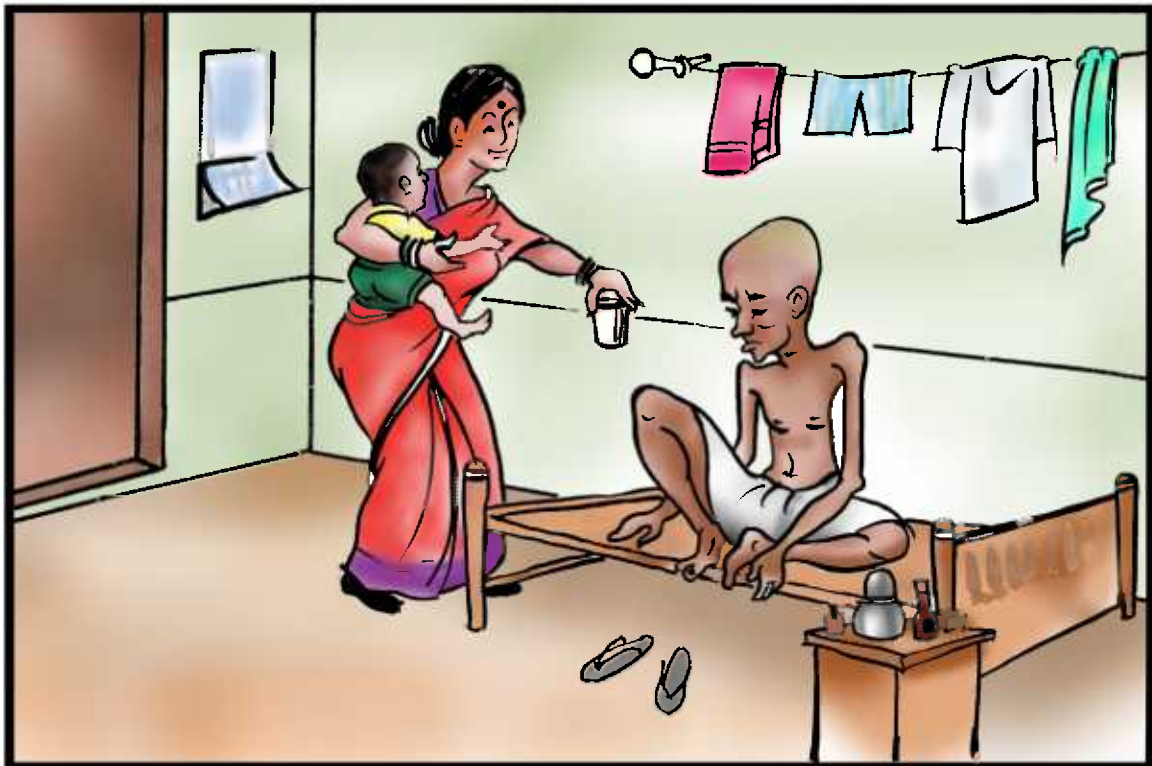
People affected by leprosy



People who are Begging



People living with HIV/AIDS



Politicians



Police



People who are transgender



Sex Workers



Elderly People



Picture cards to be used in the module 6: Exercise 6.2:

Pictures should be printed on Cards of approx. 15cm x 10cm (or near equivalent), which can be laminated for repeated use.

Street Play



Puppet show



Poster



Public speech



Radio, Television, Newspaper,



Wall writing



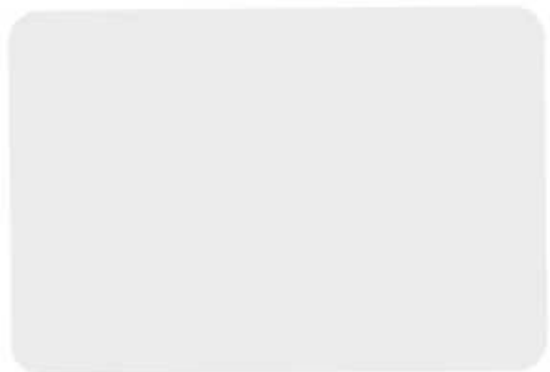
Rallies



Community meetings



Film Show



Appendix 10: Toolkits consulted for designing the CREATE toolkit

1. **Toolkit on eliminating violence against women and girls with disabilities in Fiji:**
[http://www.pacificdisability.org/getattachment/Resources/PDF-Resources/Toolkit-on-Eliminating-Violence-Against-Women-And-Girls-With-Disabilities-In-Fiji-\(1\).pdf.aspx](http://www.pacificdisability.org/getattachment/Resources/PDF-Resources/Toolkit-on-Eliminating-Violence-Against-Women-And-Girls-With-Disabilities-In-Fiji-(1).pdf.aspx)
2. **Challenging discrimination against women with disabilities: A community toolkit**
<https://www.iwda.org.au/assets/files/Triple-Jeopardy-Community-Toolkit.pdf>
<https://www.iwda.org.au/resource/triple-jeopardy-community-toolkit-2/>
3. **Mainstreaming disability in disaster management toolkit**
http://www.undp.org/content/dam/india/docs/mainstreaming_disability_in_disaster_management_toolkit.pdf
4. **Disability Inclusive Development Toolkit**
<http://www.cbm.org/article/downloads/54741/CBM-DID-TOOLKIT-accessible.pdf>
5. **Gender and violence against women and girls**
http://thoughtshopfoundation.org/project_detail/GVAWKit.html
https://issuu.com/tsfoundation/docs/gvaw_manual_en
6. **Understanding and Challenging HIV Stigma: Toolkit for Action**
<http://www.icrw.org/files/publications/Understanding-and-Challenging-HIV-Stigma-Toolkit-for-Action.pdf>
7. **Understanding and challenging TB stigma: Toolkit for action**
http://r4d.dfid.gov.uk/PDF/Outputs/Targets_RPC/TB_and_Stigma_May09.pdf
8. **The Good School Toolkit**
<http://raisingvoices.org/good-school/download-good-school-toolkit/>
9. **Advocacy Toolkit**
http://tilz.tearfund.org/en/resources/publications/roots/advocacy_toolkit/
10. **Tackling stigma in children with mental illness: A practical toolkit**
<http://www.chimat.org.uk/tacklingstigma>
<http://www.rcpsych.ac.uk/pdf/RT%20tackling-stigma-a-practical-toolkit.pdf>

References

- AGGLETON, P., K. WOOD, A. MALCOLM and R. PARKER. 2005. *HIV-related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*. UNAIDS Best Practice Collection. Geneva: USAID.
- AL JU'BEH, K. 2015. *Disability-Inclusive Development Toolkit*. Bensheim, Germany: CBM.
- AWOFESO, N. 1996. Stigma and socio-economic reintegration of leprosy sufferers in Nigeria. *Acta Leprologica*,**10**(2), pp.89-91.
- BAINSON, K. A. and B. VAN DEN BORNE. 1998. Dimensions and process of stigmatization in leprosy. *Leprosy Review*,**69**(4), pp.341-350.
- BARAC, R., S. STEIN, B. BRUCE and M. BARWICK. 2014. Scoping review of toolkits as a knowledge translation strategy in health. *BMC Medical Informatics and Decision Making*,**14**(1), pp.1-9.
- BICKENBACH, J. E., S. CHATTERJI, E. M. BADLEY and T. B. ÜSTÜN. 1999. Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science & Medicine*,**48**(9), pp.1173-1187.
- DEPARTMENT-OF-HEALTH. 2010. *Our Health and Wellbeing*. London: Department of Health.
- DEVRIES, K. M., L. KNIGHT, J. C. CHILD, A. MIREMBE, J. NAKUTI, R. JONES, J. STURGESS, E. ALLEN, N. KYEGOMBE, J. PARKES, E. WALAKIRA, D. ELBOURNE, C. WATTS and D. NAKER. 2015. The Good School Toolkit for reducing physical violence from school staff to primary school students: a cluster-randomised controlled trial in Uganda. *The Lancet Global Health*,**3**(7), pp.e378-e386.
- EBENSO, B., G. ADEYEMI, A. O. ADEGOKE and N. EMMEL. 2012. Using indigenous proverbs to understand social knowledge and attitudes to leprosy among the Yoruba of southwest Nigeria. *Journal of African Cultural Studies*,**24**(2), pp.208-222.
- GOFFMAN, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.
- HANS, A., A. M. PATEL, R. K. SHARMA, D. PRASAD, K. MAHAPATRA and R. MOHANTY. 2010. *Mainstreaming disability in disaster management: An initiative under the GOI-UNDP Disaster risk management programme*. Delhi: UNDP, India.
- HEIJNDERS, M. and S. VAN DER MEIJ. 2006. The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology Health & Medicine*,**11**(3), pp.353-63.
- HENG, C., D. TEP, H. TITH, D. TON, N. VALLINS, F. WALJI and J. ASTBURY. 2013. *Challenging Discrimination Against Women with Disabilities: A Community Toolkit*. Banteay Srei, the Cambodian Disabled People's Organisation, CBM Australia, International Women's Development Agency and Monash University.
- KAZEEM, O. and T. ADEGUN. 2011. Leprosy Stigma: Ironing out the creases. *Leprosy Review*,**82**, pp.103-108.
- KIDD, R. and S. CLAY. 2003. *Understanding and Challenging HIV stigma: Toolkit for Action--Trainer's Guide*. Washington DC: International Centre for Research on Women.
- KIDD, R., S. CLAY, S. BELEMU, V. BOND, M. CHONTA and C. CHIIYA. 2009. *Understanding and challenging TB stigma: Toolkit for action*. London, UK: International HIV/AIDS Alliance and ZAMBART Project
- KIDD, R., N. PRASAD, JYOTHSNA, M. TAJUDDIN, R. GINNI and N. DUVVURY. 2007. *Reducing HIV Stigma and Gender-Based Violence: Toolkit for Health Care Providers in India*. New Delhi, India: International Center for Research on Women (ICRW).

- LEBEL, T. 2008. Perceptions of and Responses to Stigma. *Sociology Compass*,**2**(2), pp.409-432.
- LEONARDI, M., J. BICKENBACH, T. B. USTUN, N. KOSTANJSEK and S. CHATTERJI. 2006. The definition of disability: what is in a name? *The Lancet*,**368**(9543), pp.1219-1221.
- LINK, B. G. and J. C. PHELAN. 2001. Conceptualizing Stigma. *Annual Review of Sociology*,**27**(1), pp.363-385.
- MAHAJAN, A. P., J. N. SAYLES, V. A. PATEL, R. H. REMIEN, S. R. SAWIRES, D. J. ORTIZ, G. SZEKERES and T. J. COATES. 2008. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*,**22**, pp.S67-S79
10.1097/01.aids.0000327438.13291.62.
- MAJOR, B. and L. T. O'BRIEN. 2005. The Social Psychology of Stigma. *Annual Review of Psychology*,**56**(1), pp.393-421.
- MIND.ORG.UK. 2013. *The Mind guide to advocacy* [online]. [Accessed 20 October]. Available from: <http://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/#>.
- MORRISON, A. 2000. A woman with leprosy is in double jeopardy. *Leprosy Review*,**71**(2), pp.128-143.
- NAKER, D. 2011. *The Good School Toolkit*. Uganda: Raising Voices.
- NICHOLLS, P. G., C. WIENS and W. C. S. SMITH. 2003. Delay in Presentation in the Context of Local Knowledge and Attitude Towards Leprosy—The Results of Qualitative Fieldwork in Paraguay. *International Journal of Leprosy & Other Mycobacterial Diseases*,**71**(3), pp.198-209.
- OXFAM. 2006. *Understanding gender and violence against women: Participatory Toolkit for Rural Communities--User's manual* [online]. Kolkata: Oxfam GB, East India Office. [Accessed 12 April 2016].
- PARKER, R. and P. AGGLETON. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*,**57**(1), pp.13-24.
- RAJU, M. S., P. S. S. RAO and R. K. MUTATKAR. 2014. *Eliminating Leprosy Stigma: A Manual for Community Action, Case Studies of Intervention Research in Three States*. 3rd ed. New Delhi: The Leprosy Mission Trust India, S R Health Sciences Pvt Ltd.
- SIEGEL, K., H. LUNE and I. H. MEYER. 1998. Stigma Management Among Gay/Bisexual Men with HIV/AIDS. *Qualitative Sociology*,**21**(1), pp.3-24.
- STREET, C. and S. BRENNAN. 2015. *Tackling Stigma. A Practical Toolkit: Bringing together guidance, best practice examples, case studies, resources and literature to help tackle the stigma associated with children's and young people's mental health* [online]. [Accessed 12 April].
- THOMAS, J. and A. HARDEN. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*,**8**(1), pp.1-10.
- UNITED-NATIONS. 2007. *UN Convention on the Rights of Persons with Disabilities, preamble (e)*. Geneva: United Nations.
- VAN BRAKEL, W. H. 2003. Measuring leprosy stigma—a preliminary review of the leprosy literature.[see comment]. *International Journal of Leprosy & Other Mycobacterial Diseases*,**71**(3), pp.190-7.
- VIOLETA, G. and R. QUIROGA. 2011. Stigma: The power of stigma and the power of love. *Footsteps*.**86**, pp.1-7.
- WARD, C. 2014. *Toolkit on Eliminating Violence Against Women And Girls With Disabilities In Fiji*. Suva, Fiji: Pacific Disability Forum.

- WATSON, J. 2015. *Advocacy Toolkit* [online]. 2nd ed. London, UK.: Tearfund. [Accessed 11th May 2016].
- WAXLER, N. E. 1981. Learning to be a leper: a case study in the social construction of illness. *In*: E. MISHLER, L. R. AMARASINHAM, S. T. HAUSER, R. LIEM, S. D. OSHERSON & N. E. WAXLER, ed. *Social Contexts of health, illness and patient care*. Cambridge: Cambridge University Press, pp.169-194.
- WEISS, M., J. RAMAKRISHNA and D. SOMMA. 2006. Health-related stigma: Rethinking concepts and interventions 1. *Psychology, Health and Medicine*, **11**, pp.277-287.
- WEISS, M. G. and J. RAMAKRISHNA. 2006. Stigma interventions and research for international health. *Lancet*, **367**(9509), pp.536-538.
- WHO. 2001. *International classification of functioning, disability and health* [online]. [Accessed 11 March]. Available from: <http://www.who.int/classifications/icf/en/>.
- WHO. 2011. *World Report on Disability 2011*. Geneva: WHO; The World Bank.
- WHO. 2014. *Mental Health: A state of well-being* [online]. [Accessed 20 October]. Available from: http://www.who.int/features/factfiles/mental_health/en/.
- WIKIPADIA. 2016. *Advocacy* [online]. [Accessed 20 October 2016]. Available from: <https://en.wikipedia.org/wiki/Advocacy>.
- WONG, M. L. 2004. Designing programmes to address stigma in leprosy: Issues and challenges. . *Asia Pacific Disability Rehabilitation Journal*, **15** (2), pp.3-12.
- YAMADA, J., A. SHORKEY, M. BARWICK, K. WIDGER and B. J. STEVENS. 2015. The effectiveness of toolkits as knowledge translation strategies for integrating evidence into clinical care: a systematic review. *BMJ Open*, **5**(4).
- YEO, A. 1993. *Counselling: A Problem-solving Approach*. Armour Pub.

Civil Society Organisations for Resource Mobilisation,
Empowerment, Advocacy,
Training and Employment (CREATE) Project



**The Leprosy Mission
Trust India**

healing.inclusion.dignity

**CNI Bhavan, 16, Pandit Pant Marg,
New Delhi 110001
Tel.: +91-11-43533300
Website: www.tlmindia.org**