



Fédération Internationale des Associations contre la Lèpre
International Federation of Anti-Leprosy Associations

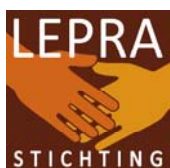
234 Blythe Road
London, W14 0HJ, UK

Tel: +44 (0)20 7602 6925
Fax: +44 (0)20 7371 1621
E-mail: ilep@ilep.org.uk
Web site: www.ilep.org.uk

Stigma Research Workshop

Report of the development of scientific consensus papers and field guidelines during the international scientific workshop on health-related stigma.

11-14 October 2010, Amsterdam, The Netherlands



Sponsored by
Netherlands Leprosy Relief and
American Leprosy Missions



Contents

	<i>Page</i>
1. Introduction	2
2. Objectives	3
3. Report of the plenary sessions	3
4. Overview of keynote presentations of current work on stigma.....	5
5. Overview of the progress made in group work on each of the themes	10
I. Research priorities in stigma	10
II. Measurement of stigma	12
III. Interventions for stigma reduction	14
IV. Counselling in relation to stigma	15
6. Brief evaluation of the workshop	17
7. Expected products and the way forward.....	18
Annexes.....	19
1. List of abbreviations	19
2. Programme.....	20
3. Participants	22

1. Introduction

A workshop was organised to produce scientific papers and field guidelines targeting health-related stigma and discrimination from 11-14 October in Hotel Casa 400 in Amsterdam, the Netherlands. This workshop brought together scientists and professionals from different public health fields to share knowledge, experiences and research findings regarding stigma and public health. By combining knowledge and experience gained in different stigma-affected conditions, a lot can be gained in the fight against stigma and discrimination in HIV/AIDS, leprosy, disability, tuberculosis and mental health. This workshop was hosted by the Netherlands Leprosy Relief (NLR) and organised in collaboration with the American Leprosy Missions (ALM). Throughout the workshop different persons were appointed as chairpersons for the plenary sessions. In the inaugural session, the 4-day meeting was opened by Dr. Wim van Brakel, member of the International Federation of Anti-Leprosy Association (ILEP) Temporary Expert Group (TEG) on Stigma and Technical Advisor of the Leprosy Unit, Royal Tropical Institute, and Mr. Jan van Berkel, Director, Netherlands Leprosy Relief.

Jan van Berkel pointed out that this workshop was of great importance to stigma-related research and practice. Although the primary interest of NLR is in leprosy, combining knowledge and experiences on health-related stigma was seen as very important. Dr Wim van Brakel referred to the background of this workshop originating in the research workshop on health-related stigma & discrimination in the Netherlands in 2004. After this, in 2005, the International Consortium for Research and Action Against Stigma (ICRAAS) was launched and the keynote papers of the workshop were published as a special issue on health-related stigma of Psychology, Health, & Medicine, in 2006. In 2007 and 2009, ICRAAS symposia were held at the International Stigma Conferences in Istanbul and London, respectively. The present workshop aimed to finalize output of a work process of the ILEP TEG on stigma which was established in 2009. After both opening speeches, each participant was given the opportunity to briefly introduce themselves by speaking about their background, interest in the field of stigma, and their expectations regarding this workshop.

The following chapters contain a brief summary of the working process, the keynote presentations and the progress that has been made on the outputs of this workshop. The report was written by Ms. Carlijn Voorend of the Netherlands Leprosy Relief, with help of Ms. Miriam Longmore, Ms. Stephanie Mak, Ms. Marlieke van der Eerden, Ms. Marije de Jong, and Ms. Sharon Stevelink, reporting on the different plenary and group sessions.

2. Objectives

The specific objectives of the workshop were as follows;

1. To identify and prioritise research needs regarding stigma and write a scientific paper on this.
2. To review instruments for measuring of stigma and write a scientific paper and field guidelines on measuring stigma
3. To identify current best practices in interventions to reduce stigma and write a scientific paper and field guidelines on stigma reduction
4. To develop review the role of counselling in relation to stigma and write a scientific paper and field guidelines on counselling in relation to stigma

3. Report of the plenary sessions

After the inaugural session, several keynote presentations were given to get a taste of current work on stigma from the perspective of different disciplines. The first presenter was Professor Patrick Corrigan, Illinois Institute of Technology, who talked about understanding stigma and stigma change in mental illness. The second keynote speaker, Professor Jayashree Ramakrishna, National Institute of Mental Health, India, spoke about the context and consequences of HIV-related stigma using data from a study she conducted in India. This was followed by a keynote presentation on disability and participatory development by Professor Ajit Dalal, Allahabad University, India. Last presenter of the morning session was Ms Zilda Borges, IDEA Brazil, who elucidated her work on counselling for stigma reduction among leprosy affected people in Brazil. After lunch, all four theme leaders provided a short presentation on each of the themes (i.e. research priorities, measurement, interventions, and counselling) to give an overview of the topics that would be addressed at the workshop through the group work. After this the plenary session ended and time was provided for separate discussion of the workplans in each of the theme groups.

The second day headed off with a keynote presentation by Professor Matthias Angermeyer, Centre for Public Mental Health in Austria, who spoke about biogenetic causal explanations of mental illness in relation to public acceptance of people with mental illness. This was followed by three short presentations of stigma research conducted in India by Master students International Public Health of the Athena Institute, VU University Amsterdam. After continuing the group work, a short plenary session for cross-fertilization of the work done in each theme group was held at the end of the day. During this plenary session time was provided for receiving feedback and input from participants of other groups. After a representative of the intervention group reported on the progress that has been made (see section 1.5 for a report of this), an attentive and vigorous but fruitful discussion followed. Concerns were voiced regarding the feasibility of delivering high quality products and producing reasoned scientific papers in four days. Also, the way to address the elusive topic of stigma with all its dimensions and the consensus needed on definitions and focus, was debated. Especially people from the intervention (Hugh Cross) and counselling (Karen Warne) groups experienced

difficulties in defining the entry point for writing the guidelines and for providing clear and simple recommendations due to a lack of any evidence. However, Wim van Brakel pointed out that, despite the huge and challenging task, there is an urgent need for clear and practical recommendations on how to deal with stigma, which have been specifically requested by the ILEP organisations. This workshop should be the first step and get the ball rolling.

On the third day, all groups continued their work on the outputs after a keynote presentation by Ms Mimi Lusli in which she spoke about her research and personal experiences while working with people affected by blindness, as she is herself.

The fourth and last day started off with a final session of cross-fertilization of the work done in each theme group. After each group presented very briefly on the status of their products, Wim van Brakel urged to the groups to write as much as possible on this last workshop day to facilitate the process of revising and finishing a final format. The aim is to finish the guidelines before the end of the year.

At the end of day four, during the final plenary session, representatives of each group briefly presented the progress made during the course of the workshop. Although none of the groups met the requirements to deliver a draft version of a scientific paper and field guidelines, an extensive amount of work was done and a lot of progress made. Each of the groups indicated needing another couple of months to finish the products and presented a time line for this. All participants were very committed to continue the joint work for a successful completion of the outputs. The final plenary session was followed by a short discussion, in which Jessie Mbwambo requested participants to send all available training materials on counseling in any stigmatised health condition to the concerned group members, and to spread this request more widely. Bassey Ebenso stated that since there are no publications on stigma-related counseling at all yet, the special issue in Leprosy Review next year might be a very good place to publish best practice paper(s), for instance on the work of Zilda Borges. Wim van Brakel commented that to get a paper in that issue, the deadline for submission is December 2010. Stigma Research and Action is a new open access e-journal which is also available for publications.

During the closing of the workshop, Dr. Wim van Brakel directed a word of thanks to all people for their active participation and in particularly to the theme group leaders. Also, gratitude was expressed to the Netherlands Leprosy Relief and the American Leprosy Missions for sponsoring the event, and to the organizing committee together with the hotel for the good organization before and during the workshop. In his closing remarks, Jan van Berkel stated that he is looking forward to see the outputs that were briefly presented in the final plenary session. He noticed that not all expectation were met yet, but he was very pleased to hear the deadlines that were set. As a final remark he stated that it is of high importance that research should inform practice and practice should inform research. Since the main focus of the NLR is on the practical side, he is therefore looking forward to receiving the final guidelines/roadmaps. However, NLR will also remain interested in scientific research on stigma.

4. Overview of keynote presentations of current work on stigma

A short summary of the keynote presentations will be provided in this paragraph, whereas the presentations will be (temporarily) available on the website of ILEP¹.

4.1 Presentation 'understanding stigma and stigma change in serious mental illness'

Patrick Corrigan from the Illinois Institute of Technology (the lead institution in the National Consortium on Stigma and Empowerment) started off by giving a presentation about '*understanding stigma and stigma change in serious mental illness*'. In this, he pointed out different approaches for achieving stigma change (i.e. social marketing, health communication, and behaviour change) with the aim or focus to address barriers to care, since stigma keeps people away from treatment. When looking at stigma throughout the history, stigma has changed but rather not positively. An increase was seen in people who believed mentally ill persons to be dangerous. Numbers showed to be twice as high in 1996, compared to 1956. Moreover, despite education, the percentage remained at the previous level of 40% in 2006. Corrigan explained how stigma could be understood and classified to change it.

When trying to understand stigma for stigma change, three basic concepts can be identified, stereotypes (people are weak, dangerous, etc), prejudice (they are bad for certain reasons), and discrimination (the behavioral result). In turn, four different types of stigma can be distinguished; the public stigma (what we do to the people), self-stigma (internalized), label avoidance (history of mental illness) and structural stigma (e.g. stigma in health services through separate treatment facilities). When people try to avoid being labelled, they may avoid seeking treatment, with the result that no labels are attached and no shame is present. Research shows that 45% would never seek care; in addition, only 22% will take the medication as prescribed. Corrigan explained that stigma change could be classified through the different vehicles (media-based or in-vivo) and the different processes of education (take the myths and contrast them with facts), contact, and protest (by reviewing stigmatizing images shame is provoked). However, in case of the latter one should be aware of a possible rebound effect, with attitude getting worse instead of better. A study conducted in 2002 by Corrigan, River et al. showed that only 'contact' had a significant effect (n=152). Also, in this study a high impact of social desirability was seen.

The effect of public service announcements is difficult to measure. When talking about stigma change in vivo, it has a large impact if people with mental illness tell their own stories. This indicates and confirms that stigma change should be targeted at local or community level. Finally, Corrigan referred to a guidebook and toolkit to beat the stigma and discrimination written by himself.

¹ <http://www.ilep.org.uk/library-resources/congresses/stigma-research-workshop-amsterdam-2010/>

4.2 Presentation 'HIV stigma – context and consequences'

Professor Jayashree Ramakrishna, an anthropologist working at the National Institute of Mental Health and Neuro Sciences (NIMHANS) in India, has been studying the social cultural aspects of health education interventions, reproductive health, and HIV/AIDS using qualitative and action research.

She presented results of a first systematic, large-scale investigation of AIDS stigma in India that examined AIDS stigma in two HIV/AIDS "high prevalence" states in India as a collaborative effort of NIMHANS, the University of California and the Tata Institute of Social Sciences. Findings were presented around test-related stigma, disclosure, disclosure-avoidance behaviour, enacted stigma, instrumental stigma, perceived stigma, internalized stigma, and consequences of stigma.

In India, the stigma around HIV is related to testing for HIV. Prof. Ramakrishna stated that HIV stigma can start affecting people even before they have been tested positive. Because the targets aim on testing, no attention is paid to counselling whatsoever. Findings showed that the majority of people tested said they were saddened after being tested. Also, some people were found to have a lack of knowledge regarding the discrimination of HIV. Overall, very little enacted stigma is reported in India, since not many people reveal their HIV status. Disclosure of the HIV status is uncommon and serious gender issues are seen related to stigma. People feel that they are bad, disgusting and so on. In India, the reason for marrying is often having a baby. When a woman has tested positive on HIV, there is a big chance that the marriage will break up, whereas this is not the case with men. Moreover, men can always re-marry and women can not. A higher level of stigma is seen especially when the concerned women are sex workers, since they are often practicing secretly, which leaves them hiding double identities. The stigma around HIV is not just a lack of knowledge, but also what people believe. For instance, nearly half of the doctors said that they take extra precautions when examining wounds, but this is not seen as stigma.

4.3 Presentation 'disability with multiple socio-economic stigmas: planning for participatory development'

Professor Ajit K. Dalal, psychologist at the Allahabad University, conducted work focussed on how cultural beliefs and attitudes play a pivotal role in exclusion of people with disability from the social mainstream. Prof. Dalal provided the following summary of his presentation.

The main thrust was physical disability as a stigmatizing condition. In many south Asian countries, the stigma of physical and mental disability is compounded by social and economic stigmas. In India, for example, more than 70 to 80 million people not only suffer from disabilities, but live also below poverty line and belong to a lower caste; they constitute the poorest among the poor. According to a World Bank Report (2007), these multiple stigmas make such persons with disabilities the most excluded group in India.

The scenario is that 836 million Indians live on \$0.5 a day and that about 40-50% of the Indian population belongs to lower castes, mostly residing in villages. Prevalence of disability is four times higher in this social group than among those who belongs to higher class castes. One can fathom that this section of the society lives in absolute poverty, without dignity and without human rights. Their access to education and employment is minimal, and they are hardly benefitting from welfare schemes. While the Indian economy is booming and middle class is burgeoning, these poorest among the poor with disability are caught in a downward socio-economic spiral.

The presentation highlighted the genesis and nature of stigma that people with disabilities suffer. Billions and billions of dollars are spent on development programmes by national and international agencies, but this has made only a marginal difference. As the data show, only 3-4% children with disabilities go to school; in higher education they constitute just 0.1% of student population. Employment has declined from 42.7% to 37.6% in a decade, affecting marginalized groups most. Employment of disabled in private sector is 0.3%, in multinational corporations 0.05%.

It was argued that active participation of these poorest people with disabilities in the developmental process is the only way to ensure their quality of life. Such participation will not occur naturally in a culture where charity, pity and welfare are the prevailing ethos. The formation of self-help groups and capacity building programmes are gradually building an environment in which this most stigmatized group is asserting and demanding participation.

4.4 Presentation 'Counselling: constructing ways to overcome stigma'

Ms Zilda Borges from Brazil gave a presentation of her experiences with counselling among leprosy-affected persons. She stressed the importance of inclusion of people affected by stigma and how the community itself identifies people who are segregated. She presented a line of care of how they work with stigma in the community and about their strategy to deal with people with self stigma. In this strategy, meetings with community members and family groups are promoted and attention is paid to affected persons who hide in their houses. Through contacting them personally via home visits and counseling, accompanied by the broader strategy of psychotherapy, self care, economic rehabilitation, advocacy and volunteer IDEA leaders, stigma is targeted.

4.5 Presentation 'Do biogenetic causal explanations increase public acceptance of people with mental illness?'

Professor Matthias C. Angermeyer is a psychiatrist working at the Centre for Public Mental Health in Austria and the Department of Public Health of the University of Cagliari (Italy). He spoke about the effect of the biogenetic model as the basis for explaining mental disorders on public acceptance of people with mental illness. Quite a few mental illness campaigns aiming to reduce stigma explicitly explain mental disorders as

biological illness, based on two assumptions. First the biogenetical causal explanations would decrease the stereotype of self-responsibility, which would lead to less exclusions. Secondly, if somebody is held less responsible for the illness, the reaction will be less unfavorable.

Prof. Angermeyer conducted a systematic review of population studies on public attitudes and beliefs about mental disorder in which four questions were addressed. The first two related to attributing mental illness to biogenetic causes and the association with, respectively, greater acceptance of those suffering from mental disorder, and lower perceptions of guilt and self-responsibility. The last two related to the prevalence of stereotypes of self-responsibility in mental illness and the association with rejection of persons with mental illness, compared to salient stereotypes of being dangerous or unpredictable. No evidence was found for an inverse association between the perception of self-responsibility and biogenetic causal attributions. Also, no or only a relatively weak relationship existed between perception of self-responsibility and desire for social distance. Moreover, a low prevalence of the stereotype of self-responsibility was found. Based on the results presented, Prof. Angermeyer stated that, contrary to the common opinion, a biogenetic causal explanation of mental disorders is not associated with less rejection of mentally ill people, and may even increase acts of social distance through perceived dangerousness/unpredictability and fear. On the contrary, biogenetic causal attributions appeared to be positively associated with perceived stigma, structural discrimination, and in help seeking of people affected. However, sufficient empirical evidence for these associations has not been presented yet. In conclusion, Angermeyer wonders whether the neuroscientific public image of psychiatry and anti-stigma campaigns are in the interest of the profession and pharmaceutical companies rather than the patients.

In the brief discussion that followed, we discussed whether this argumentation is also valid for other health-area's. Wim van Brakel stated that, sometimes, when a disease is becoming more treatable, the stigma increased, as was shown in an study on ART in HIV by Maughan-Brown et al. Angermeyer responded that he believes that the underlying fears for contagion and esthetics are much stronger forces than stigmatization. These might be a better target than noting that it is a medical disease. Hugh Cross added to this that the issue is also about the 'fear of difference'.

4.6 Presentations of three studies conducted in Tamil Nadu, India

Ms. Sara Dorsman presented about knowledge and attitudes among health care workers towards people affected by leprosy, comparing between a leprosy-specialized hospital and governmental hospitals. She concluded with three main findings. First, although a high overall mean score on a stigma scale was seen among health care workers and people affected by leprosy, no statistical difference was found between the two health care groups. Secondly, the knowledge regarding leprosy appeared to be good in both types of hospitals, but more research is needed on this among general practitioners, nurses and physician assistants. Attitudes of health care workers in a government hospital seemed less positive than in a leprosy-specialized

hospital and fear of infection was still present. To improve attitudes, it was considered important to build up a confidential bond between health care workers and people affected by leprosy.

The second presenter, Ms. Ingeborg Wu, examined knowledge and attitudes of healthcare workers (HCW) towards tuberculosis patients and the experiences of tuberculosis patients regarding HCW. Conclusions of this research included a better outcome on knowledge and attitudes of HCW than expected. However, knowledge was lacking at some points, so a need for better education and training still exists. The experiences of tuberculosis patients towards HCW were mostly positive.

The third presentation was given by Ms. Sharon Stevelink, who conducted a comparative study of stigma and social participation among persons affected by leprosy and persons affected by HIV/AIDS. The main conclusion of her work was that all respondents reported a substantial burden of internalized and perceived stigma, but that people living with HIV/AIDS reported higher levels of stigma and significantly higher levels of participation restrictions. The findings supported the possibility for developing joint interventions, such as work-related interventions, social support programmes, and integration of care in the general health system. However, she also pointed out that more research is needed on stigma among both groups and on possible joint interventions.

4.7 Presentation 'Stigma in daily life perspective'

Ms. Mimi Lusli, director of the Mimi Institute and PhD student at the VU University Amsterdam, spoke about the research she conducted and about her personal experiences while working with people who are blind like herself. By the use of five photographs she showed examples of common (negative) associations that people had with these photos. Subsequently, Ms. Lusli explained the false perception on disability in the community related to religious (sin), health (sickness), cultural (curse), educational (special), social (charity), and economic (money) views.

Ms. Lusli presented a strategy for mainstreaming disability, through emphasizing a positive image and uniqueness, considering disability to be part of human diversity and the human rights perspective, appreciating disability by 'embracing stigma' (rather than hiding from it) and by promoting inclusiveness through social marketing. The programme she developed to create more knowledge and understanding in the community is about valuing characteristics; starting with the uniqueness, then relating this to the community and eventually addressing the disability. The training is led by disabled people themselves and comprised disability sensitivity training for schools and other communities, capacity building for people living with disability, consultation and counselling, and publication through writing testimonials. Last but not least, she addressed the point that persons with disabilities should empower themselves.

5. Overview of the progress made in group work on each of the themes

Following the objectives of this workshop, four working groups were formed, each dealing with one of the following themes; research priorities regarding stigma, measurement of stigma, interventions against stigma, and counseling and stigma. The progress made during the sessions of group work in producing the requested output (scientific papers and field guidelines) will be briefly described in the following paragraphs.

I. Research priorities in stigma

The theme group on stigma research priorities worked together to identify and prioritise research needs regarding stigma, resulting in a scientific paper on the issue. In advance, theme leader Mr. Bassey Ebenso prepared a background document on research priorities in leprosy-related stigma. Group members provided input from other backgrounds in stigma research; i.e. HIV/AIDS (Dr. Sarah Stutterheim), mental health (Prof. Patrick Corrigan Mental Health, leprosy (Dr. Raju). Unfortunately, Ms. Beatriz Miranda was not able to attend the workshop but in the follow up of this workshop she will cooperate for inclusion of the focus of disability.

On the first day, after clarifying the objectives and desired output of the group work, the group agreed that the final product would exist of an opinion paper, rather than a literature review. The literature review on leprosy-related stigma, as prepared for background reading, would be submitted for publication as a stand-alone paper. Realizing the impossibility of producing a draft paper of publishable quality on health-related stigma in 3 days, the group further opted to work on an outline of a draft paper instead, aiming to complete the more comprehensive paper at a later date. Based on above decisions, Group 1 brainstormed topical/relevant issues for inclusion in the outline on health-related stigma with the intention to elaborate on the suggested issues to facilitate the paper writing at a later stage.

The leprosy-focussed background review already made clear that, although a substantial amount of literature has been published on health-related stigma, several research gaps could be identified. These, supplemented with gaps in stigma research from other health fields, according to the expertise that was present, led to the identification of 15 issues to be included in the outline of the opinion paper. These were categorized into two main topics, public health priorities and methodological considerations. During the course of the workshop, these issues were discussed extensively within the working group, resulting in four main public health priorities and four main methodological considerations.

By the end of the fourth day of group work, agreement was reached on the outline of the opinion paper. This would exist of clarification of the gaps in current research related to the public health priorities and methodological considerations as summarized in Table 1. This will be followed by recommendations given

according to the research needs and requirements for conducting high quality future research, possibly added by potential research questions in brackets.

Table 1: overview of identified research gaps and priorities

<i>Public Health Priorities</i>	<i>Methodological considerations</i>
1) Attain conceptual clarity on what stigma is	1a) Adopt participatory action research approach to stigma research (e.g. by involving persons affected by relevant conditions and other stakeholders)
2) Stigma should be studied from multiple perspectives, including a human rights approach (social model) and not just the medical/disease control perspective	1b) Research needs to inform practise and practise to inform research
3) Increase stakeholders' awareness of social history of conditions and how this shapes stigmatization.	2) Balance stigma research from the perspectives of both stigmatizers' and the stigmatized:
4) Emphasize impact of social cultural contexts on stigmatization of conditions	3) Develop robust methods for measuring stigma that account for both explicit and implicit (or unaware) prejudices that lead to discrimination:
	4) It is imperative to balance lab-based (controlled) conditions with service-oriented (real-life) research/conditions.

The first public health priority is that more conceptual clarity of what stigma is needed. For instance in the disciplinary and cultural differences in meaning of the different dimensions of stigma. Secondly, current limitations of the conceptual model relate to the focus on the medical, prevention and disease control perspective. Recognition is needed of the social history of the condition and its influence on policy and practice. Stigma should be studied from multiple perspectives including a human rights approach (i.e. the social model) and not merely from a medical or disease control perspective. Third, the need for increase of stakeholders' awareness of social history of conditions and how this shapes stigmatization was addressed. The cultural context that influences how community members (stigmatizers) and people affected by the condition (the stigmatized) perceive or experience stigma should be taken into account. Moreover, culture, context and conditions will influence the determinants and manifestations of stigma, although there are remarkable similarities in the impact of stigma across cultures & conditions. Therefore, a fourth priority was formulated emphasizing the impact of the socio-cultural contexts on stigmatization of conditions. One last point that was addressed is a remark on intervening in stigma. More research in this field is needed since education and information dissemination alone will not reduce stigma, and might even worsen it. Also, institutional and structural stigmas deserve increased attention, especially as most studies focus on the impacts of stigma on individuals and not so much on impacts on communities and societies nor policy issues and funding priorities.

Methodological considerations are often the result of unsatisfactory conceptual clarity. The question was raised how to operationalise what is considered 'good practice' in research on stigma. Systematic reviews criticise most studies for using poor research methods resulting in poor quality outcomes. Therefore,

methodological considerations on appropriate design for good quality research should be addressed and discussed. When recognizing the limits of the medical model, there is a tension between different methods that have been used. A balance is needed between the 'ideal' methodology of laboratory research and field research, which reflects reality. Ultimately, the goal is to provoke colleagues to do future research that is not only conducted from the medical perspective, but has also taken social and human rights aspects into account. In this, it is imperative to balance stigma research from the perspectives of both the stigmatizers and the stigmatized. Also, participatory action research, involving persons affected by relevant conditions as well as other stakeholders, is essential. As there are implicit and subconscious prejudices that lead to discrimination, there is a need for measures that will account for these, as well as explicit prejudices.

The two scientific papers as final products of the group work will be finalized in the coming months. The first, containing a literature review on leprosy-related stigma, is currently awaiting comments from a core group of experts and is expected to be ready for publication by the end of November 2010. For the second, consensus has been reached on the outline of a transdisciplinary opinion paper that will address conditions such as leprosy, HIV/AIDS, disability, and mental health. By highlighting important and topical issues worth researching in the immediate future, this paper should encourage researchers, practitioners and policy makers to adopt certain public health priorities and methodological considerations in their work on health-related stigma. After additional work in the coming months, this paper should be ready for publication by the end of March 2011.

II. Measurement of stigma

The group working on the topic of stigma measurement comprised people with interest in stigma from different disciplines such as leprosy (Ms. Carin Rensen, Ms. Priscila Fuzikawa, and Dr. Tiara Pakasi), mental health (Prof. Matthias Angermeyer), Leishmaniasis (Ms. Ramdas Sahiensa), HIV/AIDS (Ms. Marije de Jong), and disability (Theme group leader Dr. Wim van Brakel and Ms. Sharon Stevelink).

First the group discussed the structure of the guidelines. The document would include a flowchart in which field workers could look up the recommended measurement instrument according to the desired perspective (stigmatizer vs. stigmatized), the type of stigma and specific health condition. It was considered important to recommend both quantitative as qualitative methods. During the course of the workshop, the group was split up in two. Whereas some participants continued working on the scientific article, a somewhat larger subgroup started writing the practical field guidelines. This document would provide clear recommendations on when to use which tool. By providing examples and entrance points and by giving only the most important information needed by the field worker, it should be easy to read and practical in use.

For the quantitative measures, a set of nine criteria was formulated considered to be of importance when recommending particular instruments for generic use or cross-cultural use. These criteria were:

- proven and adequately tested psychometric properties,
- cultural validity through use in multiple countries or languages,
- appropriate length of the instrument in terms of expected time needed for assessment,
- ease of use in asking the questions,
- ease of interpretation of the outcome,
- good understandability for the respondent,
- usability across various target populations,
- frequency of (previous) use, and
- gender friendliness of the instrument.

The whole group systematically discussed all stigma measurement instruments that ranked highest in several prior literature reviews until consensus was reached on all nine criteria. Several scales were added to the list for consideration of generic use based on expert opinion. Ratings for each of the criteria were given on a four category scale (-, 0, +, ?). Table 2 shows a ‘taxonomy’ of stigma measurement instruments.

Table 2: Taxonomy of stigma measurement instruments

<i>Stigmatised</i>		<i>Stigmatisers</i>	
Internalised stigma	ISMI – generic Berger – HIV TB stigma – Tuberculosis CATIS – children	Enacted stigma	
Perceived stigma	EMICa – generic Berger – HIV TB stigma – TB DDS – mental illness	Perceived attitudes of other people	EMICc – generic DDS – mental illness
Experienced stigma	Berger – HIV DISC – mental illness	Personal attitudes: stereotypes	AQ – generic
Impact of stigma	P-scale – generic	Personal attitudes: emotional reactions	ERMIS – generic
		Personal attitudes: social distance	SDS – generic

For both products (guidelines document and scientific paper) of the measurement theme group, clear outlines were produced, as well as a working plan for finishing these outputs. A draft version of the guidelines document is expected to be ready before the end of the year. The scientific paper will contain the justification of recommended instruments by including and referring to several systematic reviews that were conducted. The group members were devoted to finish this justification paper soon. However, a comparable systematic review on HIV/AIDS was still missing and will be included before proceeding to submission. Depending on the progress made on this, the time line was set for a final draft of the paper by March 2011. Moreover, the different health condition-specific systematic reviews will also be published resulting in at least two other expected publications in advance of the overall paper.

III. Interventions for stigma reduction

The stigma intervention workgroup reached consensus on three main points. First, the impossibility to develop a single generic intervention that will suffice to address all instances of stigma. Secondly, the group decided to describe the essential features of an empowerment intervention and present the model as an example that could be replicated for stigma reduction in community contexts. Thirdly, the group endorsed the generic intervention matrix presented in the background paper written by Dr. Hugh Cross, and recommended it for the use of planning interventions.

For the scientific paper, the group considered the systematic review on successful evaluated interventions by Ms. Stephanie Mak and the draft background paper prepared by theme-leader Dr. Hugh Cross. After careful consideration, the group decided to produce two separate articles, mainly because of the large amount of information. The following persons committed to writing the scientific paper; Dr. Miriam Heijnders, Dr. Miwako Hosoda, Ms. Silatham Sermrittirong, Prof. Ajit Dalal, and Ms. Stephanie Mak.

Regarding the writing of the guidelines, consensus was reached that these would be written by Mr. Mike Idah, Ms. Mimi Lusli Dr. Miwako Hosoda, and Dr. Hugh Cross. Due to lack of scientific evidence on the effectiveness of interventions, the group agreed that the guidelines would rather be a design for developing an intervention than a recommendation of an already defined intervention. The need to be specific for intervening at the various levels was recognized; i.e. intra personal, interpersonal, organizational, community, and governmental/structural level. Furthermore, an existing toolkit for interventions for reducing HIV-related stigma, as well as social marketing as a model for intervention were discussed. However, when designing an intervention outline, one has to be specific, while many different aspects of stigma and levels for intervention could be addressed. In the meantime, the only project showing evidence of stigma reduction is the Stigma Elimination Project (STEP). The STEP project is based on knowledge, attitudes and practices-studies (KAP) and experiences gained in street dramas in Nepal. Key of the project were the self care groups which stimulated a strong identity for facilitating opportunities for stigma-affected persons to show who they are, stressing the importance of enjoying life rather than surviving life. Self care groups were considered to be useful for any kind of condition associated with impairments. Recognizing that developing one generic interventions suitable in all circumstances is impossible, the group decided that this project would be taken as a basis for the intervention guideline. However, it was noted that this is an example of an intervention, but is not the intervention. Yet, STEP has been evaluated positively and incorporated 'contact', which is recognized as an effective stigma reduction strategy in other disciplines also.

The final products of this theme-group will consist of two scientific papers and a roadmap (reformulation of previously called 'guidelines') providing detailed practical advice for project implementation. Two working titles were formulated for the scientific articles, respectively "*Literature review of stigma interventions*" and "*Stigma reduction for health conditions: suggested strategies for planning for interventions*". Drafts for all three documents are expected to be completed by the end of December 2010.

IV. Counselling in relation to stigma

The group working on counselling in stigma comprised people from India (Ms. Valsa Augustine; Theme group leader), Indonesia (Mr. Adi Yosep), Brazil (Ms. Zilda Borges and Ms. Nídia Bampirra), Nepal (Mr. Sukh Lal Singh), and the UK (Ms. Karen Warne), all working in the field of Leprosy. In addition, three persons with a more scientific background participated; Prof. Jayashree Ramakrishna from India (mental health), Dr. Jessie Mbwambo from Tanzania (HIV/AIDS), and Ms. Miriam Longmore, a medical student from the University of Oxford who has worked on leprosy and stigma in India.

The first day the group decided to focus working on the field guidelines rather than the scientific article. Subsequently, the purpose and content of these guidelines, which would actually be a 'how to do it kit' for anyone in the stigma counselling profession, were extensively discussed. After reading these guidelines the counsellor should have acquired knowledge on basic counselling and techniques used to address stigma issues. Within their role of information giving and emotional support, lay counsellors should be able to deal with the overwhelming display of emotions that will arise. Therefore, the need was addressed to write an 'emotionally inclined' document with an informational component. Because of the specificity of the matter, the group decided to restrict itself to leprosy-related stigma, rather than a broader health-related stigma focus.

Work on these guidelines was continued in all group sessions throughout the workshop. In this process, it was emphasized that the document needs to contain a description about how the guidelines should be used, a section on supervision, information on referrals, ethical guidance to ensure confidentiality, and guidance on how to apply counselling in different situations. Whereas theoretical models should not be described as such, these should be integrated into the recommendations. The group also addressed key question, such as, what is the counselling need of the person affected by stigma, and what do they need counselling for? Moreover, the discussion focussed on the process of disclosure and the fear that comes with stigma, since most affected people do not come stating they experience or suffer from stigma. The different aspects of counselling need to be described, as well as (context specific) boundaries in terms of a patient's dependency on the counsellor.

When identifying the basics of counselling, the document also needs to acknowledge the key skills of a counselling worker such as empathy, presence, ability to listen and evaluate, and the need for perseverance. During the counselling sessions, the counsellor needs to be anticipative, assess peoples need by extensive listening, making expectations of the affected person, pay attention to potential abandonment from family and friends, and need to help person understand their feelings and help them build their dignity. In this, one should keep in mind that counsellors are often volunteers and their feelings should be taken into account. Transferences and burn-out issues should be addressed, as well as how counsellors could cope with the sheer number of patients in developing countries. Moreover, paraprofessionals need to know how to come and give meaningful information to their clinical supervisors. The possibility was discussed to include scenarios or case-studies showing the counsellor how to deal with different potential problems of the client.

The following aspects were decided as final (sub) headings of the document; who this document is for, what is health related stigma in the context of counselling, introduction to counselling (including the key objectives, the counselling process, qualities of a good listener), supervision, assessment and identification of problems (pre and post), listening skills, communication skills, facilitation skills, problem solving skills, focus on feelings, focus on thinking, focus on behaviour, skills training, counsellor code of ethics, and two annexes of a leprosy fact sheet and a checklist for risk factor assessment. Work on these different subtopics of the guidelines was divided among all group members.

A working draft of these guidelines is expected in December. In the meantime, there was a call from this group for sending training manuals available in other fields of counselling as a reference, in order to develop a training manual that will aid in the use of the guidelines document. The other product is the scientific paper, which will be based on the background paper written by Ms. Valsa Augustine and Ms. Linda Adams. For this, a round of comments is scheduled in January 2011 and the deadline for a final draft of the paper set at March 2011.

6. Brief evaluation of the workshop

An evaluation form was handed out to all participants present at the final day of the workshop. Ultimately, twelve participants returned the document encompassing five brief open questions pointed to the participant about their expectations, the provided materials, organization of the conference, and the program. Responses were mainly positive and related to the interesting discussions, the broad spectrum of expertise that was present, the mix of academics and field workers, the informative and worthwhile cooperative fight against stigma, and the great atmosphere. However, the job was also considered very challenging and the wrap up time of the final presentations very short. Therefore suggestions for the programme related to a reduction of the number of participants, splitting the job in two parts, or on increasing the number of days to achieve more quality.

Discussions and talks were both challenging and enlightening

-

The workshop prompted a lot ideas that will be useful in the field

-

The discussion through group work was quite intensive and high quality.

-

Very useful to have the mix of academics and those who work in the field.

-

The concept of stigma and all its aspects have become more alive, I learned a great deal!

-

Yes, it met my expectation. We had a challenging job to do, but everyone worked really hard to finish/do the best they could. In addition, everyone was open minded and really interested to work together.

-

Though leprosy is eliminated, there is still stigma against leprosy. Long way to go to eliminate the stigma, we still need to fight against stigma.

-

I hope the whole group stays involved with all the work done and work in progress!

(quotes of workshop participants as posted on the evaluation form)

7. Expected products and the way forward

Expected drafts of scientific products:

- Research priorities regarding leprosy-related stigma (November 2010, Bassey Ebenso)
- Opinion paper for research on public health priorities and methodological considerations in health-related stigma (March 2011, Bassey Ebenso)
- Instruments recommended for measuring health-related stigma (March 2011, Wim van Brakel)
- Multiple systematic reviews on instruments used in measuring stigma in mental health, HIV/AIDS, and other health conditions (March 2011, Wim van Brakel)
- Literature review of stigma interventions (November 2010, Hugh Cross)
- Stigma reduction for health conditions: suggested strategies for planning for interventions (November 2010, Hugh Cross)
- Counselling in health-related stigma (March 2011, Valsa Augustine)

Expected field guidelines/roadmaps (December 2010);

- Interventions for stigma reduction; detailed practical advice for project implementation (Hugh Cross)
- How to measure stigma? (Wim van Brakel)
- Counselling: working with stigma in the field (Valsa Augustine)
- Counselling in health-related stigma: a training manual (Valsa Augustine)

First draft versions are expected to be ready for circulation among subgroups within the first week of December 2010, after which final drafts should be ready before the end of 2010.

Other practicalities on the way forward:

- In the first week of December, a draft of the guidelines should be circulated among the subgroups; a very short deadline will be provided for feedback and the use track changes is recommended.
- After this, only an advanced draft version of the guidelines/road maps will be circulated among the whole workshop-group (i.e. no extensive feedback loops).
- Standardization of the documents is needed; Carlijn Voorend will coordinate this in terms of layout and style for the journals/guidelines. Please send cc to her of the group correspondence.
- NLR has committed to involve a professional editor and to fund the publication of the guidelines.
- Authorship of the products: In general, papers will be attributed to the group. (Except for the papers that were produced in advance and have not changed much during the workshop) Guidelines will be attributed to the group as a whole. The (co) authors of the scientific papers will only be the ones that have contributed to the writing process.
- Guidelines will initially be published digitally on the ILEP website. Scientific papers will be submitted for publication in the new stigma e-journal (Stigma Research and Action).

Annexes

1. List of abbreviations

ALM	American Leprosy Missions
NLR	Netherlands Leprosy Relief
AIDS	Acquired Immune Deficiency Syndrome
AQ	Attribution Questionnaire
ART	Antiretroviral therapy
CATIS	Child Attitude Toward Illness Scale
DDS	Discrimination and Devaluation Scale
DISC	Discrimination and Stigma Scale
e.g.	exempli gratia; for example
EMICa	Explanatory Model Interview Catalogue for affected persons
EMICc	Explanatory Model Interview Catalogue for community
ERMIS	Emotional Reactions to Mental Illness Scale
HCW	Health care workers
HIV	Human Immunodeficiency Virus
i.e.	id est; that is
ICRAAS	International Consortium for Research and Action Against health-related Stigma
IDEA	International association for Integration Dignity and Economic Advancement
ILEP	International Federation of Anti-Leprosy Association
ISMI	Internalised Stigma of Mental Illness
KAP	knowledge, attitudes and practices
NIMHANS	National Institute of Mental Health and Neuro Sciences
P-scale	Participation scale
SDS	Social Distance Scale
SRW	Stigma Research Workshop
STEP	The Stigma Elimination Project
TB	Tuberculosis
TEG	Temporary Expert Group on stigma
UK	United Kingdom
USA	United States of America
VU	Vrije Universiteit (Amsterdam)

2. Programme

Time	Activity and objectives	
Monday 11th of October	To get a taste of current work on stigma from the perspective of different disciplines To get an overview of the work in the 4 themes to be addressed at the workshop To discuss workplans in each of the theme groups	
08.30-09.30	Registration	
09.30-10.00	Welcome on behalf of NLR; Present objectives of the workshop; explain working arrangements/logistics, "getting to know each other" (Jan van Berkel / Dr. Wim van Brakel)	Chair Dr. Hugh Cross
10.00-10.30	Keynote presentation 1; <i>Understanding Stigma and Stigma Change in Serious Mental Illness</i> (Prof. Patrick Corrigan)	
10.30-11.00	Keynote presentation 2; <i>HIV stigma - contexts and consequences</i> (Prof. Jayashree Ramakrishna)	
11.00-11.30	Coffee break	
11.30-12.00	Keynote presentation 3; <i>Disability with Multiple Socio-Economic Stigmas: Planning for Participatory Development</i> (Prof. Ajit Dalal)	
12.00-12.30	Keynote presentation 4; <i>Counselling: Constructing ways to overcome stigma</i> (Ms. Zilda Borges)	
12.30-13.30	Lunch	
13.30-13.45	Presentation working paper 1; Research priorities (Mr. Bassey Ebenso)	Chair Prof. Patrick Corrigan
13.45-14.00	Presentation working paper 2; Measurement of stigma (Dr. Wim van Brakel)	
14.00-14.15	Discussion	
14.15-14.30	Presentation working paper 3; Interventions against stigma (Dr. Hugh Cross)	
14.30-14.45	Presentation working paper 4; Counselling and stigma (Ms. Valsa Augustine)	
14.45-15.00	Discussion	
15.00-15.10	Group photo moment	
15.10-15.30	Tea break	
15.30-17.30	Group work 1 (4 groups) To discuss workplans in each of the theme groups and start the group work, if possible	
Tuesday 12th of October	To get a taste of current work on stigma from the perspective of different disciplines To work on the outputs	
08.30-08.45	Announcements	Chair Jessie Mbwambo
8.45-09.15	Keynote presentation 5: <i>Do biogenetic causal explanations increase public acceptance of people with mental illness?</i> (Prof. Matthias Angermeyer)	
09.15-10.00	'Current work' presentations of 3 short papers presenting recent work 1) <i>Knowledge and attitudes among healthcare workers towards people affected by leprosy. A comparison between a leprosy-specialized hospital and government hospitals in Tamil Nadu, India.</i> (Ms. Sara Dorsman) 2) <i>Comparison of stigma and social participation among persons affected by leprosy and persons affected by HIV/AIDS, Tamil Nadu, India</i> (Ms. Sharon Stevelink) 3) <i>Knowledge and attitudes of healthcare workers towards tuberculosis patients and the experiences of tuberculosis patients regarding healthcare workers in Vellore District, Tamil Nadu, South India.</i> (Ms. Ingeborg Wu)	
10.30-11.00	Coffee	
11.00-12.30	Group work 2 (4 groups)	
12.30-13.30	Lunch	
13.30-16.30	Group work 3 (4 groups)	
16.30-17.30	Short plenary presentations Cross-fertilization of the work done in each theme group	Chair Prof. Jayashree Ramakrishna
Wednesday 13th of October	To get a taste of current work on stigma from the perspective of different disciplines To work on the outputs	
08.30-08.45	Announcements	Chair Dr. Wim van Brakel
8.45-09.15	Keynote presentation 7; <i>Stigma in daily life perspective</i> (Ms. Mimi Lusli)	
09.15-12.30	Group work 4 (4 groups)	
12.30-13.30	Lunch	
13.30-15.30	Group work 5 (4 groups)	

Time	Activity and objectives	
15.30 onwards	Sightseeing trip and dinner	
Thursday 14 th of October	To finalise the outputs of the workshop listed on page 1	
08.30-08.45	Announcements	Chair Dr. Wim van Brakel
8.45-09.45	Plenary presentation from Theme groups Cross-fertilization of the work done in each theme group	
09.45-12.30	Group work 6 (4 groups)	
12.30-13.30	Lunch	
13.30-15.30	Group work 7 (4 groups) Finalising the draft products of the workshop	
15.30-16.00	Final plenary discussion	
16.00-16.30	Closing session "where do we go from here?" Speakers Dr. Wim van Brakel / Jan van Berkel	Chair Dr. Hugh Cross

3. Participants

Group 1: Research priorities

Dr. Bassej Ebenso – Nigeria, Leprosy
PhD student, Leeds University
(*theme group leader*)

Prof. Patrick Corrigan – USA, Mental Health²
Distinguished professor, associate dean of
research, College of Psychology, Illinois Institute
of Technology, United States of America

Ms. Marlieke van der Eerden – Netherlands²
MSc student International Public Health, VU
University Amsterdam, the Netherlands

Dr. M.S. Raju – India, Leprosy
The Leprosy Missions India Trust

Dr. Sarah Stutterheim – Netherlands, HIV/AIDS
Post-doctoral researcher, department of Work
and Social Psychology, Maastricht University the
Netherlands

Group 2: Measurement of stigma

Dr. Wim van Brakel – Netherlands, Disability
Head, Leprosy Unit, Royal Tropical Institute,
Amsterdam, Netherlands
(*theme group leader*)

Prof. Matthias Angermeyer – Germany, Mental
Health
Emeritus Professor, Director, Centre for Public
Mental Health, Gösing a Wagrem, Austria

Ms. Priscila Fuzikawa – Brazil, Leprosy
Municipal Health Secretariat, Betim, Minas
Gerais, Brazil

Ms. Marije de Jong – Netherlands, HIV/AIDS
MSc student, VU University Amsterdam,

Dr. Tiara Pakasi – Indonesia, Leprosy
Medical doctor, Leprosy and yaws control
program, MOH Indonesia

Ms. Sahiensehadebie (Sasha) Ramdas – Surinam,
Leishmaniasis
Phd student, University of Amsterdam,

Ms. Carin Rensen – Netherlands, Leprosy²
Physical therapist and medical anthropologist,
conducted research on Leprosy-related stigma

Ms. Sharon Stevelink – Netherlands, Disability
MSc student, VU University of Amsterdam,

Ms. Carlijn Voorend – Netherlands
Research fellow, Netherlands Leprosy Relief

Group 3: Interventions for stigma reduction

Dr. Hugh Cross – Philippines, Leprosy
Technical consultant, American Leprosy Missions,
and country leader Nepal, The Leprosy Mission
International
(*theme group leader*)

Prof. Ajit Dalal – India, Disability
Professor of psychology, Allahabad University,

Mr. Jonathan Dapaah – Ghana, HIV/AIDS²
Anthropologist and PhD student, University of
Amsterdam

Dr. Miriam Heijnders – Netherlands, Leprosy²
Freelance consultant, Nieuwegein, Netherlands

Dr. Miwako Hosoda – Japan, Leprosy
Research fellow, Harvard School of Public Health,
United States of America

Mr. Mike Idah – Nigeria, Leprosy
Netherlands Leprosy Relief Nigeria

Ms. Mimi Lusli – Indonesia, Disability
Phd student, VU University Amsterdam (topic of
Leprosy related disability stigma), and Director,
Mimi Institute for mainstreaming disability

Ms. Stephanie Mak – Netherlands
MSc student, VU University Amsterdam, the
Netherlands

Ms. Silatham Sermrittirong – Thailand, Leprosy/TB
Technical Officer, Raj Pracha Samasai Institute,
MOH Thailand, and PhD student, VU University
Amsterdam

² Unable to attend all four days

Group 4: Counselling

Ms. Valsa Augustine – India, Leprosy
Psychologist, Schieffelin Institute of Health-
Research and Training Centre, Karigiri, India
(*theme group leader*)

Ms. Nídia Bampirra – Brazil, Leprosy
Social worker at a clinical hospital, Brazil

Ms. Zilda Borges – Brazil, Leprosy
Counselling practitioner in Brazil

Ms. Miriam Longmore – UK, Leprosy
Student, University of Oxford, UK

Dr. Jessie Mbwambo – Tanzania, HIV/AIDS
Muhimbili National Hospital,
Department of Psychiatry and Mental Health

Prof. Jayashree Ramakrishna – India, Mental
Health
Professor and Head, Department of Health
Education, National Institute of Mental Health &
Neuro Sciences (NIMHANS), India

Mr. Sukh Lal Singh – Nepal, Leprosy
Project leader FWLCP, NLR, Dhangadhi – Kailali,
Nepal

Ms. Lendira de Sousa Fortes – Netherlands/Brazil,
Leprosy (interpreter for Ms. Zilda Borges)

Ms. Karen Warne – UK, Leprosy
The Leprosy Missions International

Mr. Adi Yosep – Indonesia, Leprosy
Project director ASEC, The Nippon Foundation
program on Leprosy and human dignity, and
board member, PerMaTa Indonesia

Participants of (parts of) plenary program, not participating in group work³

Mr. Jan van Berkel – Director, Netherlands Leprosy
Relief, Netherlands

Ms. Sara Dorsman – MSc student, VU University
Amsterdam, Netherlands, Leprosy

Dr. Henk Eggens – Medical Advisor, Leprosy Unit
Royal Tropical Institute, Netherlands

Dhr. Ruud Feijen – Psychiatrist, Amsterdam,
Netherlands

Ms. Livia van der Graaf – Project officer,
Netherlands Leprosy Relief

Ms. Roos de Groot – Research Fellow, Netherlands
Leprosy Relief

Ms. Sorana Iancu – Athena Institute, VU University
Amsterdam, Netherlands

Mr. Rens Verstappen – Head Projects Department,
Netherlands Leprosy Relief

Ms. Mathilde Vandenbooren – Project officer,
Netherlands Leprosy Relief

Ms. Ingeborg Wu – MSc student, VU University
Amsterdam, Netherlands, TB

Dr. Marjolein Zweekhorst – Athena Institute, VU
University Amsterdam, Netherlands

³ Unable to attend all four days