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WORKSHOP REPORT

Report of the Stigma Research Workshop for the development of scientific consensus papers and field guidelines on health-related stigma, held in Amsterdam, the Netherlands from 11–14 October 2010

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Summary In concurrence with the broad body of literature published on health-related stigma, there is a need for practical field guidance to contribute to the fight against leprosy-related stigma and discrimination. To this end, much can be gained by considering the accumulated knowledge and learned from experience with different stigmatising conditions; primarily HIV/AIDS, disability, tuberculosis, and mental health. Therefore a Stigma Research Workshop was organised from 11–14 October in Amsterdam, The Netherlands. The primary aim of the workshop was to produce scientific papers and field guidelines that could be used to target actions against health-related stigma and discrimination. Keynote presentations were offered by scientists and professionals from different health domains who shared their knowledge, experiences and research findings regarding health-related stigma. Group work was subsequently conducted to work towards agreed outputs on four different themes: i.e. research priorities, measurement, interventions, and counselling. The spectrum of expertise present enabled an interdisciplinary and inter-profession sharing of knowledge and practices. This resulted in the commencement of consensus papers and field guidelines related to the four themes. An evaluation by participants concluded that the workshop had been an informative and worthwhile activity that will strengthen the fight against stigma.

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1. Context

Despite the achievements in leprosy control in the past decades, there is still a stigma associated with this disease affecting current and former leprosy patients in mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions.[1] Besides leprosy, disease-related stigma is also seen in other health conditions, such as HIV/AIDS, disability, tuberculosis, and mental health. In the last decade there has been a significant increase in published work on the conceptualisation and measurement of health-related stigma and also on interventions to address it. Little has been done, however, to transmute this burgeoning literature into practical field guidelines that are required for the reduction of the impact of different health-related stigmas. In fighting leprosy-related stigma, much could be gained in accumulating knowledge and learned from experience with different stigmatising conditions.

In 2004, scientists committed to addressing stigma in different health domains attended a Research Workshop on Health-related Stigma & Discrimination, held in the Netherlands.[2] This workshop was followed by the launch of the International Consortium for Research and Action Against Stigma (ICRAAS) in 2005. It also generated the submission and publication of some keynote papers in a special issue on health-related stigma in Psychology, Health, & Medicine, in 2006. The activities of ICRAAS continued with symposia which were held at International Stigma Conferences in Istanbul and London, in 2007 and 2009 respectively. It was following this chronicle of events that the International Federation of Anti-Leprosy Associations (ILEP) established a Temporary Expert Group on stigma (TEG) in 2009. The 2010 workshop in Amsterdam aimed to finalise the output of work commissioned by the ILEP TEG on stigma.

2. Approach and objectives

The workshop was held from 11–14 October in Hotel Casa 400 in Amsterdam, the Netherlands, hosted by the Netherlands Leprosy Relief (NLR) and funded in collaboration with the American Leprosy Missions (ALM). Keynote presentations at the meeting highlighted current work from different disciplines, also introductory presentations were given providing parameters for work to be addressed by working groups. Plenary sessions also provided occasion for cross-fertilisation of ideas from the four thematic groups, but also presented opportunities for input from other participants. The following objectives of the workshop were pursued:

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. Overview of keynote presentations of current work on stigma

The following paragraphs summarise keynote presentations and progress of group work on the four themes of the workshop. The full handouts of keynote presentations are available on ILEP website and with INFOLEP information services.[*]

I Patrick Corrigan – Understanding stigma and stigma change in serious mental illness

Patrick Corrigan, of Illinois Institute of Technology and the National Consortium on Stigma and Empowerment, USA, underlined approaches to achieve stigma change (i.e. social marketing, health communication, and behaviour change) specifically addressing barriers to care, since stigma keeps people away from treatment. He highlighted how stigma has changed throughout the history, albeit negatively.

Corrigan suggested three basic concepts which should be identified when trying to understand stigma: i) stereotypes e.g. perceived dangerousness of people with mental illness, ii) prejudice e.g. perceived reasons why people with mental illness are considered 'bad', and iii) discrimination e.g. behavioural outcomes of stereotypes/prejudices. He suggested further that four different types of stigma can be distinguished; i) public stigma (what we do to the people), ii) self-stigma (internalised), iii) label avoidance (in relation to seeking help) and iv) structural stigma (e.g. stigma in health services through separate treatment facilities). To emphasise his view Corrigan reported that the numbers of those people who believed that people with mental illness could be dangerous was twice as high (40%) in 1996 compared to 1956. Despite educational interventions, by 2006 this percentage had not changed.

In label avoidance, 45% of the people would never seek care because they prefer to avoid the shame of being labeled as 'mad', and only 22% adhere to prescribed medication. Corrigan explained that the course of achieving stigma change could be classified according to the different vehicles (media-based or in-vivo) versus three strategies of education (e.g. myths contrasted with facts), contact, and protest (by reviewing stigmatising images shame is provoked). He warned that there is a potential rebound effect with the latter strategy; attitudes can worsen rather than improve through protest.[3] In a study conducted in 2001 by Corrigan, River *et al.*, it was only 'contact' that had a significant effect ($n = 152$) on reducing the stigma of mental illness.[4] The effect of public service announcements is difficult to measure. The largest impact of in-vivo stigma change was achieved when people with mental illness told their own stories; a finding which suggested that stigma change tactics should be targeted at local or community level. Corrigan, in conclusion, referred to a guidebook and toolkit to address the stigma and discrimination associated with mental illness that he had written[†].

II Jayashree Ramakrishna – HIV stigma: context and consequences

Professor Jayashree Ramakrishna, of the National Institute of Mental Health and Neuro Sciences (NIMHANS) in India, presented results of a first systematic, large-scale study examining AIDS stigma in two HIV/AIDS 'high prevalence' states in India. This was a

[*] http://www.ilep.org.uk/library-resources/congresses/stigma-research-workshop-amsterdam-2010/; http://infolep.org

[†] http://www.NCSE1.ORG

collaborative effort of NIMHANS, the University of California, San Francisco and the Tata Institute of Social Sciences. Findings focused on the following themes: test-related stigma, disclosure, disclosure-avoidance behaviour, enacted stigma, instrumental stigma, perceived stigma, internalised stigma, and consequences of stigma.

Findings showed that in India HIV stigma affected people prior to being tested positive. Nevertheless, the target-oriented nature of testing meant insufficient attention is paid to counselling. A majority of people who had been tested reported that they had been saddened and a third were frightened by the positive test results. There was a reluctance to disclose HIV status, and the consequences of disclosure were modulated by gender, social status and affiliation to a minority group. The potential for marriage break-ups, for example, was higher when women tested positive for HIV than when men tested positive. Men, moreover, found it easier to re-marry than women. A higher level of stigma was common among female sex workers, and since some of them practise secretly, this leaves them hiding double identities. Female sex workers, and men who have sex with men, thus face redoubled discrimination and stigma. Such factors provoke self stigma or internalised stigma and leaves some affected people convinced that their disease is a retribution for moral depravity. Overall, enacted stigma is rare, as most people conceal their HIV status. In India, HIV/AIDS stigma is not just due to a lack of knowledge, but also appears to be linked to perceived vulnerability and ground realities.[5–8]

III Ajit Dalal – Disability with multiple socio-economic stigmas: planning for participatory development

Professor Ajit K. Dalal, of Allahabad University, focused on the role of cultural beliefs and attitudes in the exclusion of people with disability from mainstream Indian society. He highlighted that physical disability constituted a stigmatising condition and that the stigma of physical and mental disability is compounded by social and economic stigmas. He cited, for example, that between 70 to 80 million people in India with disabilities live below the poverty line and/or belong to a low caste and, as such, they constitute the poorest of the poor. He added that it was these multiple stigmas that make such people with disabilities the most excluded group in India.[9] Disabled people have restricted access to education, employment and benefit from welfare schemes. He articulated the dilemma that whilst the Indian economy is booming and the Indian middle class is burgeoning, economically poor disabled people are caught in a downward socio-economic vortex.[10]

Dalal acknowledged that the active participation of the poorest disabled people in the developmental process is arguably the only way to ensure an enhanced quality of life for them. Such participation, however, is unlikely to occur in a culture where charity, pity and welfare are the prevailing ethos. The progressive establishment of self-help groups and capacity building programmes will help to ensure stigmatised groups can assert and demand participation.

IV Zilda Borges – Counselling: constructing ways to overcome stigma

Ms. Zilda Borges of the International Association for Integration, Dignity and Economic Advancement (IDEA), Brazil, gave a presentation on her experiences with counselling among leprosy-affected people. She stressed the importance of including people stigmatised by leprosy in the programme she had developed. Personal interactions within the community can identify people prone to self-stigmatisation and exclusion. The strategy gives importance to meetings with community members and family groups, as well as to the initiation of proactive ways of including people affected by leprosy who ordinarily hide themselves. Targeted home visits and counselling are integral to a broader strategy of psychotherapy, self-care, economic rehabilitation and advocacy. She advocated this combination of tactics to achieve stigma reduction.

V Matthias Angermeyer – Do biogenetic causal explanations increase public acceptance of people with mental illness?

Professor Matthias C. Angermeyer of the Centre for Public Mental Health (Austria) and the Department of Public Health of the University of Cagliari (Italy), spoke about the effect of the biogenetic model as the basis for explaining mental disorders on public acceptance of people with mental illness. Mental illness campaigns aiming to reduce stigma are often based on this model, following two assumptions: i) biogenetical causal explanations would decrease the stereotype of self-responsibility, leading to less exclusion, and ii) when a person affected is held less responsible for their illness, the public reaction will be less unfavourable.

Findings of a systematic review of population studies on public attitudes and beliefs about mental disorders were presented. These were not found to be supportive of the assumptions suggested above. Findings showed that biogenetic attributes were positively associated with social distance, rather than negative association as was expected. It was found, furthermore, that empirical evidence to support a relationship between biogenetic causal attributions and a lower perception of guilt and self-responsibility was lacking.

Another finding was that there was only a relatively weak relationship between perception of self-responsibility and desire for social distance compared to the salient stereotypes of being dangerous or unpredictable. Dangerousness, however, did appear to be associated with a larger desire for social distance. A final finding of note was that the stereotype of self-responsibility towards people with mental illness was much less frequently endorsed than expected. The only exception to this was the condition of alcoholism for which people affected were generally considered to be responsible for the social distance the condition excites. Based on the results presented and contrary to common opinion, a biogenetic causal explanation for mental disorders does not appear to reduce the incidence of rejection of mentally ill people. A biogenetic causal explanation may even lead to the desire for an increased social distance through perceived dangerousness/unpredictability and fear. The attribution of biogenetic causes may, however, have potential for positive effects on perceived stigma, structural discrimination, and in intentions for help seeking by mentally ill people. However, sufficient empirical evidence for these associations has not been presented yet. In conclusion, Angermeyer argued that promulgating biogenetic causal models may not be a rational and evidence based strategy to decrease discrimination against people with mental illness but that they may actually lead to an increase of mental illness stigma.

In the brief discussion that followed, it was debated whether this argument might also be valid for other health domains. Van Brakel stated that, sometimes, as a disease becomes more treatable, the stigma associated with it increases, as was shown in an study of ART in HIV by Maughan-Brown.[11] Angermeyer responded that he believed that the underlying fears for contagion and esthetic considerations are much stronger forces than stigmatisation. He suggested, furthermore, that these might be a better target than noting that a condition is a ‘medical disease’. Cross added to this that the issue is also about the ‘fear of difference’.

VI Sara Dorsman, Ingeborg WU, and Sharon Stevelink – Presentations of three studies conducted in Tamil Nadu, India

Ms. Sara Dorsman presented a study of knowledge and attitudes related to leprosy among health care workers (HCW) in a specialist leprosy hospital compared with comparable HCW in governmental hospitals. She concluded that: i) no statistical difference was found between the two groups of HCW on knowledge even though there was a high overall mean score for stigma relating to people affected by leprosy; ii) while knowledge of leprosy was satisfactory in both types of hospitals, attitudes of HCW in a government hospital seemed less positive than in a leprosy-specialised hospital and fear of infection was still present; iii) to improve attitudes, it was important to improve trust between HCW and people affected by leprosy.

Ms. Ingeborg Wu reported on knowledge and attitudes of HCW towards tuberculosis patients and the experiences of tuberculosis patients regarding HCW. She concluded that the experiences of tuberculosis patients were mostly positive, and that knowledge and attitudes of HCW were better than expected. She recommended better education and training and training of HCW.

Ms. Sharon Stevelink presented findings of a comparative study of stigma and social participation among people affected by leprosy and those living with HIV/AIDS. She concluded that while all respondents experienced significant burdens of internalised and perceived stigma, people living with HIV/AIDS suffered higher levels of stigma and significantly higher levels of participation restrictions. She also concluded that there is potential for developing joint interventions, for example: employment interventions, social support programmes, and integration of care in the general health system.

VII Mimi Lusli – Stigma in daily life perspective

Ms. Mimi Lusli, director of the Mimi Institute[‡] and PhD student at the Vrije Universiteit Amsterdam, shared her experiences of working with other blind people. With the aid of five photographs she provided examples of common (negative) associations. She explained that false perceptions about disability in the community are related to religion (sin), health (sickness), culture (curse), education (special), social conscience (charity), and economy (money).

She also suggested a strategy for mainstreaming disability, through emphasising positive images and uniqueness regarding disability as part of human diversity whilst also stressing the human rights perspective. She advocated the appreciation of people with disability and suggested ‘embracing stigma’ (rather than hiding from it). She also suggested promoting inclusiveness through social marketing. Her strategy and its accompanying disability-sensitivity curriculum for schools and communities are designed to be implemented by

[‡] http://www.mimiinstitute.com

people with disabilities. The aim is to promote self-empowerment of persons with disabilities and their inclusion in society.[12]

4. Overview of progress of group work on the themes

I. RESEARCH PRIORITIES IN STIGMA

The theme group on stigma research priorities identified priorities for stigma research, resulting in a scientific paper on the issue. In advance of the workshop, theme leader Dr. Bassey Ebenso, prepared a background document on research priorities in leprosy-related stigma to be submitted for publication as a stand-alone paper. Group members with expertise in HIV/AIDS, mental health, and disability provided ideas for writing the outline of an opinion paper on health-related stigma in the duration of the workshop, aiming to complete the more comprehensive paper at a later stage.

Following the review of existing literature on health-related stigma, 15 issues were identified for inclusion in the opinion paper. These were categorised into two main topics namely, public health priorities and methodological considerations. Following extensive discussion, the 15 issues were grouped into four public health priorities and four methodological considerations. The paper aims to encourage researchers and policy makers to adopt certain public health priorities and methodological considerations in their work on health-related stigma (see Table 1 below).

The four public health priorities include the need for conceptual clarity on stigma-seeking cross-disciplinary consensus about different dimensions of stigma. Secondly, recognising the limits of the medical/disease control model, the study of stigma should be broadened to include the human rights/social model. Thirdly, it is pertinent to raise stakeholders' awareness of the influence of social history of stigmatising conditions (e.g. leprosy, mental illness and disability) on policy and practice. Fourthly, consideration should be given to the influence of cultural contexts on how community members (stigmatisers) and people affected by the condition (the stigmatised) perceive or experience stigma.

Table 1. Overview of identified research gaps and priorities

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

As methodological considerations often result from conceptual perspectives, consideration for appropriate design for good quality research should be discussed and addressed. A balance is also needed between the 'ideal' methodology of laboratory research (e.g. controlled trials) and field research, which reflects reality. Thirdly, a balance of research from the perspectives of both stigmatisers and the stigmatised as well as participatory action research, involving people affected by relevant conditions and other stakeholders is essential. Lastly, 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.

II. MEASUREMENT OF STIGMA

The group working on the topic of stigma measurement comprised people with an interest in stigma from different disciplines, including: leprosy, mental health, leishmaniasis, HIV/AIDS, and disability more generally. The group began by discussing 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 (stigmatiser vs. stigmatised), the type of stigma and specific health condition. It was considered important to recommend both quantitative as qualitative methods. This document would provide clear recommendations on when to use which tool. The guide should be made easy to read and practical to use because it will provide examples and entrance points and will give only the most important information needed by the field worker.

For the quantitative measures, a set of nine essential criteria was formulated. The criteria were considered salient recommendations for instruments to be considered 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,
- easy for respondents to understand,
- usability across various target populations,
- frequency of (previous) use, and
- gender friendliness of the instrument.

The group systematically discussed all stigma measurement instruments that ranked highest in several prior literature reviews until consensus was reached on all criteria for which information was available. 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 showing how the selected instruments relate to the various aspects of stigma that may be measured.

The scientific paper will contain the justification for recommended instruments based on systematic reviews that have been conducted. Further health condition-specific systematic reviews will also be prepared which will result in at least two more publications in advance of the principal paper. The group members made a commitment to expedite the completion of the justification paper. Clear outlines and a working plan for finishing the expected products (guidelines document and scientific paper) were drawn up.

Table 2. Taxonomy of stigma measurement instruments

Stigmatised		Stigmatisers	
Internalised stigma	ISMI – generic Berger – HIV TB stigma – tuberculosis CATIS – children	Enacted stigma	No instrument recommended
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 Personal attitudes: social distance	ERMIS – generic SDS – generic

ISMI = Internalized stigma of Mental Illness scale; Berger-HIV = HIV Stigma Scale developed by Berger *et al.*; CATIS = Child Attitude Toward Illness Scale; EMICa = Explanatory Model of Interview Catalogue for use among persons affected by a health condition; EMICc = Explanatory Model of Interview Catalogue for use among community members; DDS = Devaluation and Discrimination Scale; DISC = Discrimination and Stigma Scale; AQ = Attribution Questionnaire; P-scale = Participation Scale; ERMIS = Emotional Reactions to Mental Illness Scale; SDS = Social Distance Scale.

III. INTERVENTIONS FOR STIGMA REDUCTION

The stigma intervention workgroup reached consensus on three main points. First, the group agreed on the impossibility of developing a single generic intervention that will suffice the requirement to address all instances of stigma. Secondly, the group decided to describe the essential features of an empowerment intervention and to 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 use in the planning of interventions. After careful consideration, the group decided to reproduce the systematic review on successful evaluated interventions by Ms. Stephanie Mak and the draft background paper prepared by theme-leader Dr. Hugh Cross as two separate articles, mainly because of the large amount of information.

Due to lack of scientific evidence on the effectiveness of interventions, the group agreed that it was more appropriate to offer guidelines rather than a specific design for developing an intervention. There was, however, agreement that there is a need to be specific to ensure appropriate intervention at the various levels of stigma: i.e. intra personal, interpersonal, organisational, community, and governmental/structural level. Recognition was also given to an existing toolkit for interventions for reducing HIV-related stigma. The strong support for a social marketing model for an intervention was also considered. A major challenge is that the design of an intervention needs to consider multiple aspects if the complexity of stigma is to be addressed. One project that did seek to address the range of different levels of stigma was the Stigma Elimination Project (STEP). The STEP project was stimulated by a knowledge, attitudes and practice study (KAP) following public awareness campaigns (primarily street drama) in Nepal. That KAP survey revealed that although there was a change in knowledge of leprosy there had not been a significant change in attitude or behaviour towards people affected by leprosy.[13] The key components of the intervention that followed were the activities of self-care groups. These extended beyond individual impairment control to the initiation and facilitation of simple development activities that benefitted the communities in which the self-care groups functioned. Through these initiatives the groups developed strong identities which won the respect of their communities.

Having agreed that the development of one generic intervention to be applied for all stigma situations did not appear possible, the group decided that the STEP project methodology could be presented as an example to guide others who might be interested to know how an empowerment intervention could be applied. The intervention has features of a social marketing approach (social marketing as an approach to intervention has strong proponents) but it also has other features which have been identified as having positive effects on discrete levels of stigma: contact, education and training.

The products this theme-group will offer comprise the following: two scientific papers and a roadmap (reformulation of what had previously been called ‘guidelines’) providing detailed practical field advice for an empowerment project. Two working titles were formulated for the scientific articles, respectively: “Interventions for Stigma Reduction – Part 1: Theoretical Considerations” and “Interventions for Stigma Reduction – Part 2: Practical Applications”.

IV. COUNSELLING IN RELATION TO STIGMA

The group working on counselling in stigma comprised people from the field of leprosy, mental health, and HIV/AIDS. On the first day the group decided to focus attention on the field guidelines rather than the scientific article. Subsequently, the purpose and content of the proposed guidelines were extensively discussed. (The guidelines will essentially be a ‘how to do it kit’ for anyone committed to stigma counselling). The intention is that the guidelines will equip counsellors with essential knowledge on basic counselling techniques used to address stigma issues. Beyond the expected functions of information supply and emotional support, lay counsellors need to be able to deal with the overwhelming display of emotions that can arise. The need was acknowledged, therefore, 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 continued throughout the working group sessions. It was emphasised 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 a key question: “what is the counselling need of a person affected by stigma, and what do stigmatised people need counselling for?” The discussion continued with a greater focus on the process of disclosure and the fear that comes with stigma since it was suggested that most affected people do not present stating they experience or suffer from stigma. It was also suggested that 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.

In the identification of the essentials of counselling, the document will need to acknowledge the key skills of a counselling worker such as empathy, presence, ability to listen and evaluate, and the need for perseverance. During counselling sessions, counsellors need to be anticipative. They are required to assess people's need by extensive listening; make expectations of the affected person; pay attention to potential abandonment from family and friends; and help people to understand their feelings with the goal of building their dignity.

Another important consideration must be that counsellors are often volunteers and their feelings should also be taken into account. Transferences and burn-out issues should be addressed, as should a counsellor's capacity to cope with the sheer number of patients in developing countries. Paraprofessionals, furthermore, need to know how to approach and give meaningful information to their clinical supervisors. Different scenarios or case-studies were presented to demonstrate how counsellors might deal with different potential problems that clients might present.

The following aspects were finalised: (sub) headings of the document; who the 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, and problem solving skills; focus on feelings, thinking and behaviour; and counselling code of ethics. There will also be two annexes which will include a leprosy fact sheet and a checklist for risk factor assessment.

In order to develop a second (training) manual that will aid the use of the guidelines document, the group requested all participants to send, if available, training manuals in other fields of counselling. The third product of this group will be a scientific paper, based on the background paper written by Ms. Valsa Augustine and Ms. Linda Adams.

5. Conclusion, expected products and the way forward

The Stigma Research Workshop in general was a groundbreaking attempt at producing practical guidance in the fight against health-related stigma and discrimination. The broad spectrum of expertise consisting of a mix of academics, field workers and policy makers from diverse health fields, resulted in informative and valuable contributions that will strengthen the fight against health-related stigma.

Throughout the workshop, concerns were voiced regarding the feasibility of delivering high quality products and producing reasoned scientific papers in four days. Ways to address the complex topic of stigma with all its elusive dimensions was were debated and the need for a consensus on definitions and focus was identified. During the workshop the lack of scientific evidence on the topic of counselling in stigma and on stigma-reduction interventions hindered the development of evidence-based guidelines for field use. It was agreed therefore that discrete approaches to counselling and intervention are required for any stigmatising health condition. Undaunted by this challenge, participants did their utmost to achieve ILEP's request for clear and practical recommendations and guides for dealing with stigma. The outcomes of this workshop should therefore be considered another step at ensuring research informs practice and practice informs research.

Although none of the four groups met the requirements of producing draft versions of scientific papers and field guidelines by the end of the workshop, a lot of progress was made, and reasonable deadlines were set. The groups made commitments to finalising their products within the months following the workshop, based on an agreed time lines.

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References

[1] Van Brakel WH, Khawas IB, Lucas SB. Reactions in leprosy: an epidemiological study of 386 patients in west Nepal. *Lepr Rev*, 1994; **65**: 190–203.
[2] Somma D, Bond V. Editorial: International research workshop on health-related stigma and discrimination. *Psychol Health Med*, 2006; **11**: 271–276.
[3] Corrigan P. How stigma interferes with mental health care. *Am Psychol*, 2004; **59**: 614–625.
[4] Corrigan PW, River LP, Lundin RK *et al.* Three strategies for changing attributions about severe mental illness. *Schizophr Bull*, 2001; **27**(2): 187.
[5] Ministry of Health, Family Welfare Government of India. HIV Sentinel Surveillance and HIV Estimation in India 2007: A Technical Brief, National AIDS Control Organisation. October 2008.
[6] Steward WT, Herek GM, Ramakrishna J *et al.* HIV-related stigma: adapting a theoretical framework for use in India. *Soc Sci Med*, 2008; **67**: 1225–1235.
[7] Unnikrishnan B, Mithra PP, Rekha T, Reshmi B. Awareness and attitude of the general public toward HIV/AIDS in coastal Karnataka. *Indian J Comm Med*, 2010; **35**: 142–146.
[8] Van Hollen C. HIV/AIDS and the Gendering of Stigma in Tamil Nadu, South India. *Cult Med Psychiatry*, 2010; **34**: 633–657.
[9] World Bank R. People with disability in India. From commitments to outcomes – Released in New Delhi. Washington, DC: World Bank 2008.
[10] Dalal AK. Disability-Poverty Nexus: Psycho-social impediments to participatory development. *Psychol Dev Soc*, 2010; **22**: 409–437.
[11] Maughan-Brown B. Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Soc Sci Med*, 2010; **70**: 368–374.
[12] Hendriks V. Visions on Mainstraiming Disability in Development. Strengths, Weaknesses, Opportunities, Constraints. Unpublished thesis 2009.
[13] Cross H, Choudhary R. STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal. *Lepr Rev*, 2005; **76**: 316–324.

Annex: List of participants in alphabetical order per group, with country and field of (research) interest

Group 1: Research priorities	1*	Prof. Patrick Corrigan	USA	Mental Health	Illinois Institute of Technology, USA
	2^	Dr. Bassey Ebenso	Nigeria	Leprosy	Leeds University, UK
	3*	Ms. Marlieke van der Eerden	Netherlands	Leprosy	VU University Amsterdam, Netherlands
	4	Dr. M.S. Raju	India	Leprosy	The Leprosy Missions India Trust
	5	Dr. Sarah Stutterheim	Netherlands	HIV/AIDS	Maastricht University, Netherlands
Group 2: Measurement	7	Prof. Matthias Angermeyer	Germany	Mental Health	Centre for Public Mental Health, Austria
	6^	Dr. Wim van Brakel	Netherlands	Disability	Royal Tropical Institute, Amsterdam, Netherlands
	8	Ms. Priscila Fuzikawa	Brazil	Leprosy	Municipal Health Secretariat, Betim, Brazil
	9	Ms. Marije de Jong	Netherlands	HIV/AIDS	VU University Amsterdam, Netherlands
	10	Dr. Tiara Pakasi	Indonesia	Leprosy	Leprosy sub-division, Ministry of Health, Indonesia
	11	Ms. Sahienshadebie Ramdas	Surinam	Leishmaniasis	University of Amsterdam, Netherlands
	12*	Ms. Carin Rensen	Netherlands	Leprosy	Freelance consultant, Netherlands
	13	Ms. Sharon Stevelink	Netherlands	Disability	VU University Amsterdam, Netherlands
	14	Ms. Carlijn Voorend	Netherlands	Leprosy/Mental Health	Netherlands Leprosy Relief, Netherlands
Group 3: Interventions	15^	Dr. Hugh Cross	Philippines	Leprosy	American Leprosy Missions, Philippines, and The Leprosy Mission International, Nepal
	16	Prof. Ajit Dalal	India	Disability	Allahabad University, India
	17*	Mr. Jonathan Dapaah	Ghana	HIV/AIDS	University of Amsterdam, Netherlands
	18*	Dr. Miriam Heijnders	Netherlands	Leprosy	Freelance consultant, Netherlands
	19	Dr. Miwako Hosoda	Japan	Leprosy	Harvard School of Public Health, USA
	20	Mr. Mike Idah	Nigeria	Leprosy	Netherlands Leprosy Relief, Nigeria
	21	Ms. Mimi Lusli	Indonesia	Disability	VU University Amsterdam, Netherlands, and Mimi Institute for mainstreaming disability, Indonesia
	22	Ms. Stephanie Mak	Netherlands	Public Health	VU University Amsterdam, Netherlands
	23	Ms. Silatham Sermrittirong	Thailand	Leprosy/TB	Raj Pracha Samasai Institute, Thailand, and VU University Amsterdam, Netherlands
Group 4: Counselling	24^	Ms. Valsa Augustine	India	Leprosy	Schieffelin Institute of Health-Research and Training Centre, India
	25	Ms. Nídia Bambirra	Brazil	Leprosy	Hospital das Clínicas da Universidadae Federal De Minas Gerais, Brazil
	26	Ms. Zilda Borges	Brazil	Leprosy	International association for Integration Dignity and Economic Advancement, Brazil
	27	Ms. Miriam Longmore	UK	Leprosy	University of Oxford, UK
	28	Dr. Jessie Mbwambo	Tanzania	HIV/AIDS	Muhimbili National Hospital, Tanzania
	29	Prof. Jayashree Ramakrishna	India	Mental Health	National Institute of Mental Health & Neuro Science, India
	30	Mr. Sukh Lal Singh	Nepal	Leprosy	Netherlands Leprosy Relief, Nepal
	31	Ms. Lendira Sousa Fortes	NL/Brazil		(Interpreter for Ms. Zilda Borges)
	32	Ms. Karen Warne	UK	Leprosy	The Leprosy Missions International, UK
	33	Mr. Adi Yosep	Indonesia	Leprosy	The Nippon Foundation program on Leprosy and human dignity, and PerMaTa, Indonesia

Annex: *continued*

Not participating in group work	34*	Mr. Jan van Berkel	Netherlands Leprosy Relief, Netherlands
	35*	Ms. Sara Dorsman	VU University Amsterdam, Netherlands
	36*	Dr. Henk Eggens	Royal Tropical Institute, Netherlands
	37*	Dr. Ruud Feijen	Psychiatrist, Amsterdam, Netherlands
	38*	Ms. Livia van der Graaf	Netherlands Leprosy Relief, Netherlands
	39*	Ms. Roos de Groot	Netherlands Leprosy Relief, Netherlands
	40*	Dr. Sorana Iancu	VU University Amsterdam, Netherlands
	41*	Mr. Rens Verstappen	Netherlands Leprosy Relief, Netherlands
	42*	Ms. Mathilde Vandenbooren	Netherlands Leprosy Relief, Netherlands
	43*	Ms. Ingeborg Wu	VU University Amsterdam, Netherlands
	44*	Dr. Marjolein Zweekhorst	VU University Amsterdam, Netherlands

* Attended only part of the time, ^ group theme leader.