

# VU Research Portal

## Assessing health-related stigma and social participation

Stevelink, S.A.M.

2011

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### ***citation for published version (APA)***

Stevelink, S. A. M. (2011). *Assessing health-related stigma and social participation: research methods are coming of age.*

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

## CHAPTER 1

### General introduction

“We, ourselves, exist” (Rene Descartes).

## I. General background

*“I perceived myself, quite accurately unfortunately, as having a serious mental illness and therefore as having been relegated to what I called “the social garbage heap”. ... I tortured myself with the persistent and repetitive thought that people I would encounter, even total strangers, did not like me and wished that mentally ill people like me did not exist. Thus, I would do things such as standing away from others at bus stops and hiding and cringing in the far corners of subway cars. Thinking of myself as garbage, I would even leave the sidewalk in what I thought of as exhibiting the proper deference to those above me in social class. The latter group, of course, included all other human beings” (p. 407-408) (1).*

This quote illustrates two important concepts in my thesis: stigma and participation. Many people living with disabling conditions, such as leprosy, HIV/AIDS, spinal cord injury, physical disabilities and mental illness, are stigmatized because of these conditions (2-4). Stigma negatively impacts on many important life domains, such as domestic life, employment, educational opportunities, interpersonal relationships and family life (4). Often, the stigma is even more destructive to the affected person than the disabling condition itself (2). The restrictions people experience are usually in the life domain called ‘social participation’ (4-9).

Stigma and participation are complex dynamic constructs. Due to their complexity, past investigations focussed primarily on the qualitative assessment of both concepts (10-12). However, over the years progress has been made to in the understanding of both concepts, and with that, in the quantitative measurement of each. With help of such instruments it was becoming possible to measure, e.g. the effectiveness of public health interventions. However, attempts at quantitative measurement gave rise to two important practical needs: 1) the need to test the psychometric properties of these measures and compare these to international benchmarks, and 2) the need to test whether measures are culturally valid for use in the particular study context. Two practical tools were identified that can be used for addressing these needs. The first concerned quality criteria for what constitute good psychometric properties and the second the development of a cultural equivalence framework (13;14). This thesis reports on how we operationalized these tools in the field of participation and stigma measures in low- and middle-income country settings.

In this chapter, I will first conceptualise stigma and participation in relation to the International Classification of Functioning, Disability and Health (ICF) (15). After the conceptualization, an exploration of the concept of participation is given, followed by a section focussing on stigma. The

assessment of stigma and participation is addressed after and followed by the aim of the thesis. This chapter closes with research questions, the research methodology and thesis outline.

## **II. International Classification of Functioning, Disability and Health**

Since 1980, the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which was introduced by the World Health Organization (WHO), was commonly used as a uniform classification system of social health (16). The ICIDH served several purposes, including evaluating the effectiveness of health care processes related to chronic diseases, disorders and impairments (16;17). As these conditions are persistent, a need was identified for a model describing the consequences of those conditions over time (16;17).

The ICIDH framework consisted of three components; impairment, disability and handicap. Impairment referred to the “abnormalities of body structure and appearance and with organ or system function, resulting from any cause”, whereas disabilities concerned “the consequences of impairment in terms of functional performance and activity by the individual” (16;17). Handicaps reflected “the disadvantages experienced by the individual as a result of impairments and disabilities” (16;17). According to the ICIDH, often a typical pattern could be identified, whereby a disease or disorder resulted in an impairment (17). The consequences of the impairment may lead to a disability. Finally this resulted in a handicap, reflecting the subjective experience of the consequences of impairments and disabilities (17).

The ICIDH framework facilitated in the understanding of the disablement process (16). However, the main limitation of the ICIDH was the exclusion of contextual factors, such as personal factors and the environment, from the model that conceptualised the disablement process (18). Furthermore, the ICIDH conceptualized disability and handicap as linear consequences of ill health (medical model of disability), whereas the ICF integrates disability in a bio-psychosocial model of health and functioning (15;16). In the 1990s, the medical model was severely criticized, particularly by representatives of the disability movement (19). As a result, the ICIDH was replaced by the ICF in 2001. The ICF focuses especially on the interaction between personal factors, environmental factors, the health condition and their impact on functioning (Figure 1) (20).

The ICF comprises three components namely the *health condition*, functioning, and contextual factors and will be the main theoretical framework in this dissertation (Figure 1) (15;20). The first component, *health condition*, refers to the presence of diseases, disorders and injuries. Below I elaborate on the second and third component.

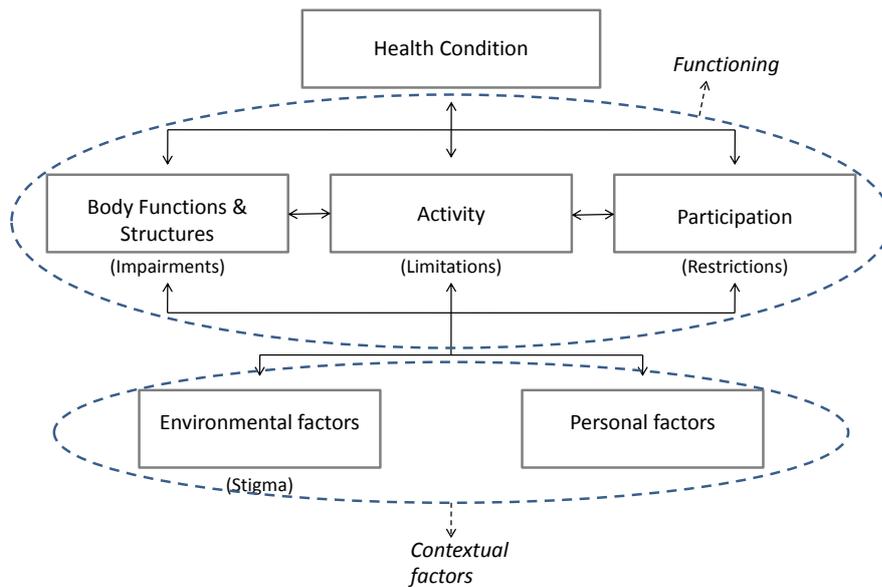


Figure 1: International Classification of Functioning, Disability and Health

### *Functioning*

The second component, the functioning (and possible limitations in functioning) is divided in three subcomponents namely *body functions & structures*, *activity* and *participation*. *Body functions* are defined as “physiological functions of body systems”, whereas *body structures* refer to “the anatomical parts of the body such as organs, limbs and their components” (15;20). Examples for the former include mental, sensory, voice and speech functions. Examples of body structures include structures related to the eye, ear, skin or nervous system (16;20). *Activity* is envisioned as “the execution of specific tasks or actions by an individual, whereas *participation* is defined as “involvement in life situations” (15;20).

The execution of daily tasks, for example in domestic and civic life, and/or the participation in festivals and other social gatherings may be affected by a particular *health condition*. A *health condition* may negatively affect the functioning at the level of the body or body parts, the person or the functioning of the person in a social context. This process of disablement may involve *impairments*, *activity limitations* or *participation restrictions*, defined as “problems in body function or structure such as significant deviation or loss”, “difficulties an individual may have in executing activities” and “problems an individual may experience in involvement in life situations”, respectively (15;20). Please refer to section three for a detailed description about the construct of participation.

### *Contextual factors*

The third component, contextual factors, is divided in two subcomponents named *Personal factors* and *Environmental factors* (15;20). *Personal factors* relate to the individual background of the person and includes characteristics such as age, gender, education, personality, social status, life style etc (15;20). *Environmental factors* “make up the physical, social and attitudinal environment in which people live and conduct their lives”. This includes the natural environment and human-made changes to the environment, but also support and relationships, services, systems and policies (15;20). These *Environmental factors* may positively or negatively affect the individual. *Stigma* is part of the *Environmental factors*, in which attitudes, values and beliefs concerning a particular disabling condition may negatively affect the person involved (Figure 1) (15;20). Section four of this chapter provides a detailed description of health-related stigma.

### *Disability*

As this thesis will focus especially on persons living with disabling conditions, the concept of disability is defined, based on terminology used in the ICF, as “a difficulty in functioning at the body, person or societal level in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors” (21).

### **III. Participation**

Participation is one of the focal points in this thesis and therefore an elaboration is provided in this section. This concept is often recognized as an important indicator for assessing the effectiveness of rehabilitation programmes (22).

Although in some contexts, ‘social participation’ can be seen as a component of ‘participation’ as defined in the ICF, these two terms will be used interchangeably to address this concept throughout this thesis (23). Social participation refers explicitly to the social interactions persons have with others in their environment (24). However, in our studies we focussed on participation in general and no distinction was made between the two concepts.

### *Definition of participation*

It is important to note that discussions are on-going about the definition of participation and what participation actually comprises (25;26). The level and type of participation varies among individuals, so participation may have different meanings and may be dynamic across a person’s life span. Furthermore, the definition proposed by the WHO makes no clear distinction between activity and participation (25;27-29). Other definitions of participation focus on a life course perspective,

including a hierarchical approach comprising the different development stages across the life span of an individual, or the inclusion of a disability rights perspective (25). According to the Disability Creation Process proposed by Fougeyrollas and colleagues, social participation reflects an interaction between intrinsic factors (personal) and extrinsic factors (environmental). These authors used the concept of 'life habits' to define social participation as 'those habits that ensure the survival and development of a person in society throughout life' (30;31).

We decided to use the definition of participation as proposed in the ICF, because this framework is widely known and used throughout the world (32). In addition, the ICF was used as the theoretical foundation of the Participation Scale. This scale was one of the main instruments used during this dissertation project.

#### *Participation in the ICF*

According to the ICF, participation comprises nine life domains, namely learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life (15;20). Within each life domain, several aspects of participation were identified. Examples include walking and moving (mobility), household tasks (domestic life) and employment (community, social and civic life) (15;20). Topics covered within these aspects may range from travelling outside of the village, visiting places of religious worship, doing the dishes and looking after the children to talking with friends and attending social gatherings.

#### *Restrictions in participation*

Due to a disabling condition, people may experience participation restrictions in these life domains. Restrictions are often reported in the performance of (heavy) household tasks, mobility, involvement in community life, employment, education and social relationships (6-8;33-35). These restrictions in participation are situated in the component 'Functioning' of the ICF (Figure 1, previous section). However, as the Figure indicates, there is an interaction within this component as well as between the two other components; *health condition* and contextual factors.

The severity of these participation restrictions may be influenced by several factors related to the *health condition*, such as visibility of the disability, severity of impairment and the level of activity limitations (7;36-38).

In the component contextual factors, the level of participation restrictions may be influenced by *personal factors*, such as gender and income level (8;39;40).

However, participation restrictions, do not only result from these *personal factors*, the *environment* also plays a major role. The availability of family and/or presence of social support is important. However, factors perhaps cited more often than others are negative attitudes and other forms of stigma (41). Stigma can have a profoundly negative impact on the lives of affected people. The association between stigma and participation can be illustrated by the following examples.

*“Anand is 27 years old and was diagnosed with leprosy a year ago. People in his community believe leprosy is a curse, only those who have committed sins in their past can get leprosy and that persons with leprosy should not participate in religious festivals. Anand starts believing this about himself. He stops going to the temple, does not leave his house anymore and believes he must be a bad person”* (p. 8) (42).

#### **IV. Health-related stigma**

Stigma is an important concept that cannot be discussed without reference to Goffman, who described stigma as an “...attribute that is deeply discrediting...” (p. 3), and “an undesired differentness” (p. 5) (43). Stigma may cause a person to be “...reduced...from a whole and usual person to a tainted, discounted one” (p. 3) (43).

During the years this definition has been challenged for several reasons. One of the most important reason being the definition of stigma as a static phenomenon, which does not account for the observed variations in stigma (41;44). This resulted in several other definitions focusing especially on health-related stigma in the dynamic, socially complex society where we live in (41;45-48). The definition of health-related stigma adopted in the present thesis is: “a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group” (p. 280) (41).

#### *Causes of stigma*

Several causes of stigma have been identified and these may vary across health conditions. People may fear the affected person, because they think the condition is contagious and are afraid they may catch the disease also, resulting in status loss and family problems (49-51). Concerning other conditions, people think that affected persons are dangerous and may lose control (epilepsy,

schizophrenia) (52;53). Affected persons may be afraid for the reactions from their husband or community members (54). A lack of knowledge about the transmission process, treatment perspectives and associated morbidity and mortality may result in stigmatizing behaviour (47;54-56). The presence of strong cultural or religious beliefs may also influence this process. In some cases, affected persons are blamed because they are believed to have 'committed a sin' or to be cursed because of misbehaviour (52;57). A particular example of that is the association with immoral behaviour, often reported in relation to HIV/AIDS stigma (2;42;58).

#### *Consequences of stigma*

Stigma have been shown to negatively impact not only the person affected, but also the community and even public health programs and interventions (4). A review conducted in 2006, suggests that these effects are remarkably similar across countries and in different health conditions under study (4). Examples of the impact of stigma include increased mortality and morbidity, isolation, secrecy concerning the condition, problems in friendships and relations, but also delay in help-seeking behaviour, poor treatment adherence, continued transmission of the health condition and risk of drugs resistance (4;9;48;59-64).

#### *Levels of health-related stigma*

According to the literature and specifically outlined by Livingstone and Boyd, stigma occurs at three different levels namely the macro, meso and micro level (41;44;46-48;65). In addition, several types of stigma can be distinguished at these levels. *Institutional stigma* refers to the stigma that exists at system (macro) level and was defined as "the rules, policies, and procedures of private and public entities in positions of power that restrict the rights and opportunities of people with disabling conditions" (p. 2151) (44). *Public stigma* occurs at the group (meso) level and can be defined as "the phenomenon of large social groups endorsing stereotypes about and acting against a stigmatized group" (p. 179) (65). Internalized, perceived and experienced stigma exists at the level of the *individual* (micro).

#### *Public stigma*

Various types of *public stigma* can be defined according to a framework proposed by Weiss (3). The stigmatizers may actually *enact stigma*, thereby "actively engaging in the process of exclusion, using their power to discriminate unfairly, ostracizing, or actively troubling someone whom they regard to be unacceptable" (p. 3) (3). Discrimination can therefore be seen as an expression of *enacted stigma*. On the other hand, people may refrain from actively engaging in the process of enacting stigma, but "may endorse it, justifying and supporting exclusion though they themselves refrain, owing to legal

or moral constraints”(p. 3) (3). This type of stigma is called *endorsed stigma*. The third type of public stigma is *accepted stigma*. People may reject the stigmatizing behaviour of others, but will do nothing to stop it from happening (3). “They accept it, without endorsing it”(p. 3) (3).

### *Individual stigma*

*Individual stigma* is one of the focal points in this thesis. Several types can be distinguished.

*Internalized stigma* is defined as a “subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation or stereotype endorsement resulting from an individual’s experiences perceptions or anticipation of negative social reaction on the basis of their health condition” (p. 2151) (44). Persons living with a disabling condition may feel disappointed in themselves for being affected, ashamed, isolated and inferior compared to others (9;66;67). Internalized stigma is often the result from prolonged exposure to *perceived stigma*, “negative consequences resulting from an individual’s awareness of how society perceives and will likely act toward the group to which they belong” (p. 2151) (44), and/or *experienced stigma*, “experience of actual discrimination (p. 334) (4) and/or participation restrictions on the part of the person affected”(p. 307) (4), that influence the affected person (4;46;68). Therefore, *the enacted stigma* perpetrated by the stigmatizers, is reflected as *experienced stigma* by the stigmatized. The interaction between the different types of stigma is illustrated in Figure 2 (based on Pryor and Reeder, in press). This Figure suggests interrelatedness of the different types of individual stigma. The different types of public stigma affect the stigma experiences of the individual.

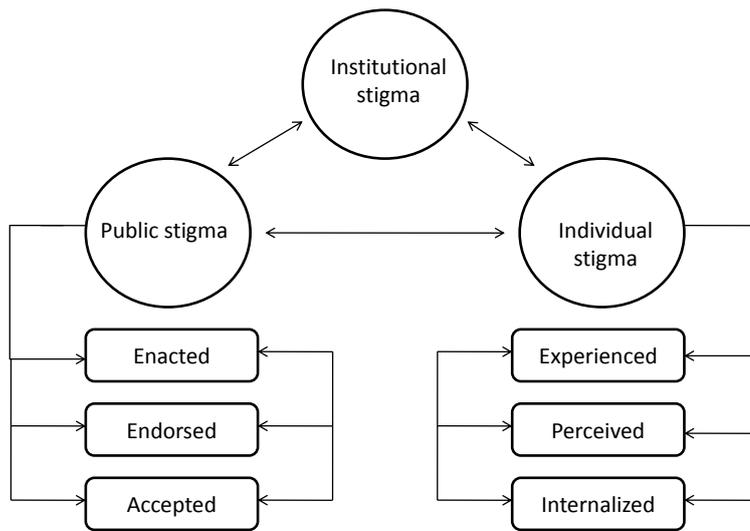


Figure 2: Description of the interaction between the different types of stigma (based on Pryor and Reeder, in press)

#### V. Assessment of stigma and participation

The fact that a given health condition may be stigmatized and/or cause restrictions in social participation is well known. Various studies showed that stigma and participation restrictions are highly prevalent across health conditions such as HIV/AIDS, leprosy and mental illness (1;69-71). Many of them have used qualitative methods including in-depth interviews, focus group discussions and observational studies to obtain insight in both concepts. Compared to the data provided by quantitative instruments, they provide a richer contextual background for the interpretation of the findings (72). However, a main limitation of these methods is often the small number of participants and therefore limited generalizability of the results (72).

Much progress has been made in understanding stigma and participation and, as a result, in our ability to measure these phenomena. Over recent years, more and more measures have become available. With the availability of these measures it is now possible to address stigma and participation in a quantitative manner, for example, to assess the impact of stigma reduction interventions. Widely applied examples of the instruments to assess participation include the Participation Scale (P-scale) (23), the Assessment of Life-Habits (LIFE-H) (31) and the Impact on Participation and Autonomy (IPA) (73), whereas often used stigma instruments include the Internalized Stigma of Mental Illness (ISMI) scale (74), the Explanatory Model Interview Catalogue (EMIC) (71) and the Berger HIV Stigma Scale (75). These are briefly discussed below. However, only

few measures have been validated for use in low- and middle-income country settings or across different health areas.

The use of quantitative measures is not straightforward in low- and middle income countries. A substantial proportion of the target group may be illiterate, not used to answering items with fixed response categories or used being asked for their opinion about something. The phrasing of the items, as statements or questions also needs consideration. Therefore, it is very important that an instrument and its use are tailored or adapted to the specific needs of the target population. Examples included the contextualisation of the wording of items, the adaptation of the method of administration of the instrument, rephrasing response options and using native speakers as interviewers.

During the research for this dissertation several quantitative measures were used.

#### *The Participation Scale*

The P-scale can be used to assess perceived participation restrictions (23). The scale is based on the participation domains of the ICF, as described in the section 'Participation' of this chapter. The P-scale is an 18-item measure and has six potential response options; the same as everyone else (0 points), not relevant (0), no problem (1), small problem (2), medium problem (3) and large problem (5). The sum score of the items is the total score on the scale. The higher the score, the higher the level of participation restrictions (23).

An important characteristic of the P-scale is the use of the 'peer' concept. In the majority of the items, participants are asked to compare themselves with a peer, defined as "those who are similar to the respondent in all respects except for the disease/disability" (23). This concept was introduced to facilitate the comparison of present participation levels with levels before the disease or disability developed. In addition, it was hypothesized that the use of the 'peer' concept may prevented the comparison with inappropriate persons who may be different from the participant for other reasons than the condition being studied. In most studies no problems were reported with the use of this concept. However, some problems were reported with the peer concept during studies in Indonesia (76). The concept was found to be too abstract or no appropriate translation could be found (76). In these cases, a particular (named) peer was identified with help of the respondent and used to facilitate the comparison process.

We decided to use the P-scale, because the scale was especially developed for use in low- and middle income settings, already widely applied and showed good psychometric properties (23;37;77;78).

#### *The Explanatory Model Interview Catalogue*

The EMIC intends to measure the level of perceived stigma (71). The scale covers several aspects of perceived stigma, such as concealment, avoidance, pity and shame. A four-point answer option is used ; yes (3 points), possibly (2), and no (0). The higher the sum score on the EMIC, the higher the level of perceived stigma. During a previous study in India, the EMIC showed good results. Therefore the instrument was also included in our field studies (37;71).

#### *The Internalized Stigma of Mental Illness Scale*

The ISMI was used to measure the level of internalized stigma (74). The instrument consists of 28 items and has a four-point agreement scale. The ISMI consists of five subscales named alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance (74). A mean item score is calculated, whereby a higher score indicates a higher level of internalized stigma. This instrument was already applied previously in a leprosy-affected population and intends to be generic in nature (37;74). Therefore the ISMI was also used in our study.

#### *The need for valid instruments for application in low- and middle-income countries*

Validated measures are necessary to make comparisons between health or social programmes, interventions and strategies and to provide evidence for their effectiveness. Evidence is needed concerning both “best practices” and interventions that have not been successful to inform policy, practice and research (4;41;79). Furthermore, it is important to show whether stigma and participation restrictions are still present, to what extent, and whether specific attention is necessary to address both problems. An overview of the extent and severity of stigma and participation restrictions in a given setting or target group can be used for advocacy purposes and awareness raising as well as to inform policy development to safeguard the rights of persons affected by disabling conditions. In addition, adequate assessment will increase our understanding of both phenomena and allow us to investigate the underlying determinants and dynamics. These data may provide leads for designing appropriate interventions to reduce stigma and improve social participation (4;41;79). A combination of qualitative with quantitative methods often provides the best results.

The majority of the measures have been developed in Western countries and quite a few are transferred for use to developing countries (4;26;28;44;68). The need for high-quality instruments to

assess health-related outcomes, such as participation and stigma, is nowadays pressing in developing countries. In the past, communicable diseases accounted for most of the morbidity and mortality burden in developing countries. However, the burden of non-communicable diseases is now rapidly increasing, leaving these countries with a double burden of disease (80). This shift, as well as an increased life-expectancy, an increased rate of traffic and other accidents, and increases in armed conflict lead to an increase in chronic disabling conditions, resulting in even more than a double burden of disease (32;81;82). Often such conditions lead to stigma and/or participation problems (32). This in turn increases the demand for valid tools to measure these phenomena reliably.

#### *Practical conditions for measures*

To use such measures two practical conditions need to have been met: 1) they have sound psychometric properties and 2) they are culturally valid for the setting they are to be used in. Both conditions will be explained into more detail in the following paragraphs.

#### Psychometric properties

Several developments have occurred in the field of health measurement that may help us to meet these conditions. Psychometric methods used in instrument development and validation have evolved rapidly, resulting in a comprehensive set of quality criteria that provide indications for what constitute good psychometric properties (14). These quality criteria have been developed by Terwee et al. and comprise all key psychometric properties including content, criterion and construct validity, internal consistency, agreement, reliability, responsiveness, floor and ceiling effects and interpretability (14). In this framework it is exactly stated which statistical methods to use for addressing these psychometric properties and when the results found on these properties can be identified as good (14). Please refer to Chapter 4, Appendix 1 for a complete overview of this framework.

Recently, the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) study used an international Delphi panel to reach consensus on the classification, terminology and definitions of psychometric properties in the area of health measurement (83-85). Furthermore they identified suitable statistical methods for testing these and scoring of the results found (86). In the present thesis the quality criteria were used as the basic principles, whereas some of the concepts presented by the COSMIN consortium were added (See Chapter 3 and Chapter 4). We were not able to use or test the COSMIN scoring system, since this was only published very recently (86).

## Cultural equivalence

The cultural validity of a specific measure in a given context and for a particular target group has also been recognized as very important. The evaluation of “the extent to which an instrument is suitable for use in a different culture from the one it was initially developed for”, is called ‘cultural equivalence’ testing (Stevenson et al. submitted). Cultural equivalence should be evaluated in detail, before an instrument is used in a new cultural setting (13;87). This is particularly important for constructs such as participation and disability that may be conceptualized differently in different cultures (88). If important differences are identified during a validation study, for example in the conceptualization of the particular concept under investigation or the appropriateness of the measure, a decision has to be made to adapt the measure, or in the worst case, that the measure is not suitable for use in that particular setting (See Chapter 6) (13;87).

In 1998, Herdman et al. proposed a framework for testing cultural equivalence (13). The framework was adapted for use in the current thesis and comprises five key categories of equivalence; conceptual, item, semantic, operational and measurement. In its original form, the framework comprised six categories of equivalence, including functional equivalence. This term was used as an umbrella category, summarizing the results found on the other five categories. We decided to replace this category with ‘cultural equivalence’, defined in the previous paragraph. In addition, some small adaptations were made to the sub-categories of equivalence. Please refer to Chapter 6 for more details.

Conceptual equivalence was described as the domains that are important to measure the underlying concept of an instrument (13). Item equivalence was described as the acceptability and relevancy of the items to tap the construct of participation, whereas semantic equivalence was concerned the “transfer of meaning across languages” (p. 326) (13). Operational equivalence refers to the possibility of using “a similar questionnaire format, instructions, mode of administration and measurement methods” (p. 329) (13). These four types of equivalence can be assessed by using qualitative methods such as in-depth interviews with the target population, experts or researchers, focus group discussions and by conducting extensive literature research. Measurement equivalence, “the extent to which the psychometric properties of different language versions of the same instrument are similar”, can be examined by investigating psychometric properties as internal consistency, reliability, construct validity and responsiveness (p. 330) (13). In this thesis research, we have tried to integrate the insights from this framework with recent development in psychometric testing and have applied this to cross-cultural measurement of social participation.

## **VI. Aim of the thesis**

In this thesis, I build on the above developments, namely the quality criteria for psychometric properties and the cultural equivalence testing framework. I aim to take these a step further by applying them in the field of participation and stigma measures and by testing them in a low- and middle-income setting. Based on the results of this research, a framework was developed integrating psychometric and cultural equivalence testing relevant to such measures.

## **VII. Research questions**

This thesis addresses several research questions. The questions themselves and the rationale for each are described below.

A review published by van Brakel in 2006 suggested that effects of stigma and participation restrictions were remarkably similar across study populations and disabling conditions (4). This conclusion was based on a detailed investigation of common items used across instruments and across multiple health conditions. Extensive similarity was found particularly across items used in leprosy and HIV/AIDS measures. However, actual comparative field studies were scarce. Therefore I aimed to provide insight in the level of internalized and perceived stigma, and participation restrictions between these health conditions. Three widely applied measures were used; the ISMI, the EMIC and the P-scale, respectively. This led to the following research question.

1. What are the differences and commonalities in the level of stigma and participation restrictions among persons living with HIV/AIDS and persons affected by leprosy in Southern India? (Chapter 2)

As described above, the P-scale was used to assess participation restrictions during the first field study conducted in Southern India. We decided to select this measure, because it was explicitly developed for use in low- and middle-income countries and already applied widely. The P-scale was used to test the utility of the new quality criteria developed for testing psychometric properties in a low-income country. The proposed quality criteria were not available at the time of the original development study of the P-scale. We considered it useful to submit the instrument to this, more rigorous testing protocol, to see if it could stand up to these new standards. This study was conducted in a different country than the first field study, because we aimed to investigate the stability of the psychometric properties of the P-scale in more than one country and different study populations. This led to the second research question.

2. What are the psychometric properties of the P-scale in a study population consisting of people with various disabilities living in Eastern Nepal? (Chapter 3)

During the studies conducted, I focused on testing the psychometric properties of the P-scale. However, research suggested that health-related stigma and in particular internalized stigma are important contextual factors that may affect social participation (9;37). For the accurate assessment of internalized stigma, it is important that the measures used are valid and reliable. Therefore I applied the current quality criteria framework, to work done in the area of internalized stigma measures. This led to the following research question.

3. How is internalized stigma conceptualized and to what extent is it being measured adequately? (Chapter 4)

At the time of writing this thesis, the P-scale is available in at least 25 languages. However, not all studies have been published yet (9;37;77;78;89;90). Based on field experiences from researchers that used the P-scale, including my own, and findings from the second field study performed in Nepal, the need for a shortened version for use in surveys was identified (Stevelling et al. accepted) (Beise, and van Brakel, personal communication). A shortened version of the P-scale may result in a reduced emotional burden for the participants and a decrease in administration time. Furthermore, during the field study performed in Nepal, a two-factor structure for the P-scale was found, instead of a unidimensional model of participation, as identified during the initial development study (23). This finding may have implications for the use and statistical analysis of the P-scale. Taking into account these considerations, I formulated the fourth and fifth research questions.

4. Can the P-scale be shortened, without negatively affecting the psychometric properties of the scale? (Chapter 5)
5. What factor structure best fits the P-scale data from various study populations? (Chapter 5)

While focusing on the cross-cultural testing of psychometric properties, the wider concept of testing cultural equivalence acquired attention. Many instruments have been developed in Western countries and are transferred for use to low- and middle-income countries. It is important to check if an instrument is suitable for use in a different culture than initially developed for, that adaptations are necessary, or in the worst case scenario, is not suitable for use in that context. Otherwise the results found may not present a realistic interpretation of the situation. A conceptual framework was

identified that could be used to assess this process of cultural equivalence testing (91). This led to my final research question.

6. To what extent is cultural equivalence testing addressed in cross-cultural validation studies of participation measures? (Chapter 6)

### **VIII. Research design and outline of the thesis**

Several field studies and systematic reviews have been undertaken to answer the research questions.

A cross-sectional field study was performed from April till July 2009 in Southern India. Participants affected by leprosy and participants living with HIV/AIDS were included from several hospitals, charity projects and during home visits. Three quantitative instruments, the ISMI, the EMIC and the P-scale, were used to assess internalized stigma, perceived stigma and social participation, respectively. This study aimed to identify possible commonalities and differences in stigma and participation between both respondents groups, thereby answering the first research question. The study was partly funded by the Netherlands Leprosy Relief and the Dittmer Fund. Please refer to Chapter 2 for detailed information.

From July 2010 till October 2010, a cross-sectional study was conducted in Eastern Nepal. This study was designed to further validate the P-scale using recently developed state-of-the-art statistical methods. These methods were defined using the quality criteria proposed by Terwee et al. (14). The criteria were used to investigate the psychometric properties of the P-scale among participants with various disabilities. Participants were included using a systematic random sampling method. Besides the P-scale, a perceived stigma scale was administered during community visits. The study aimed to assess the psychometric properties of the P-scale, including internal consistency, construct validity, reliability and floor and ceiling effects, thereby answering the second research question. No external funding was available for this study. Chapter 3 presents the findings from this study.

From May till June 2011, a systematic review was written describing the assessment of psychometric properties in the field of internalized stigma measures. This review was designed to investigate whether the quality criteria were met in this particular area of health measures (research question three). Four literature databases, *Pubmed*, *PsycINFO*, *Web of Science* and *CINAHL*, were systematically searched for internalized stigma development or further validation studies. The studies included were assessed using quality criteria for what constitute 'good' psychometric

properties. This review was partly funded by VU University Amsterdam. The results can be found in Chapter 4.

As already described, the P-scale is a widely applied measure. Shortening of the instrument may benefit its use, because it will result in a decreased administration time and impose less of a burden for the participants. By approaching previous and current users of the P-scale, a large multi-country database from multiple cultures was compiled. The statistical programme Mplus was used to develop the Participation Scale Short (research question four). In addition, the optimal factor structure of the P-scale was defined, using explanatory and confirmatory factor analyses, thereby answering research question five. The results of this research, funded by VU University Amsterdam, are described in Chapter 5.

The majority of the instruments to measure participation have been developed in Western countries. Many of these are transferred to middle and low income countries. Before operationalization of these instruments in this new study setting, it is important to investigate whether they are suitable for use in a different culture than initially developed for. Therefore we decided to review the process of cultural equivalence testing in this field, thereby answering research question six. This systematic review was performed in July and August 2011. Three literature databases, *Pubmed*, *PsycINFO* and *Web of Science*, were searched to include participation measures and further validation studies. Two independent raters assessed the measures included, using an integrated framework that consisted of conceptual, item, semantic, operational and measurement equivalence. The main findings and their implications are described in Chapter 6. This review was funded by VU University Amsterdam.

A detailed exploration of the results found in the different field studies and systematic reviews is provided in the Discussion. Besides this detailed exploration, take-home messages are described and a reflection on the methodology is provided. This chapter closes with future research priorities.

## Reference List

- (1) Gallo KM. First person account: self-stigmatization. *Schizophrenia Bulletin* 1994;20(2):407-10.
- (2) Mak WW, Mo PK, Cheung RY, Woo J, Cheung FM, Lee D. Comparative stigma of HIV/AIDS, SARS, and tuberculosis in Hong Kong. *Social Science and Medicine* 2006 October;63(7):1912-22.
- (3) Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Neglected Tropical Diseases* 2008;2(5):e237.
- (4) Van Brakel WH. Measuring health-related stigma--a literature review. *Psychology Health and Medicine* 2006 August;11(3):307-34.
- (5) Grech S. Living with disability in rural Guatemala: exploring connections and impacts on poverty. *Disability, Community and Rehabilitation* 2008;7(2).
- (6) Lund ML, Nordlund A, Nygard L, Lexell J, Bemspang B. Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury. *Journal of Rehabilitation Medicine* 2005 January;37(1):3-8.
- (7) Rusch M, Nixon S, Schilder A, Braitstein P, Chan K, Hogg RS. Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality Life Outcomes* 2004;2:46.
- (8) McKibbin CL, Twamley E, Patterson TL, Golshan S, Lebowitz B, Feiner L et al. Perceived participation restriction in middle-aged and older persons with schizophrenia. *American Journal of Geriatric Psychiatry* 2008 September;16(9):777-80.
- (9) Stevelink SAM, Van Brakel WH, Augustine V. Stigma and social participation in Southern India: Differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. *Psychology Health and Medicine* 2011 February 28;1-13.
- (10) Ingram D. HIV-positive mothers and stigma. *Health Care for Women International* 1999;20(1):93-103.
- (11) Moneyham L, Seals B, Demi A, Sowell R, Cohen L, Guillory J. Perceptions of stigma in women infected with HIV. *Aids Patient Care and Standards* 1996 June;10(3):162-7.
- (12) Lawlor K, Mihaylow S, Welsh B, Jarvis S, Colver A. A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. *Developmental Neurorehabilitation* 2006;9(3):219-28.
- (13) Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. *Quality of Life Research* 1998 May;7(4):323-35.

- (14) Terwee CB, Bot SDM, De Boer MR, van der Windt DAWM, Knol DL, Dekker J et al. Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology* 2007 January;60(1):34-42.
- (15) World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO; 2001.
- (16) World Health Organization. *International Classification of Impairments, Disabilities and Handicaps*. Geneva: WHO; 1980.
- (17) Gray DB, Hendershot GE. The ICDH-2: Developments for a new era of outcomes research. *Archives of Physical Medicine and Rehabilitation* 2000 December;81(12):S10-S14.
- (18) Badley EM. The genesis of handicap: definition, models of disablement, and role of external factors. *Disability and Rehabilitation* 1995;17:53-62.
- (19) Pfeiffer D. The ICDH and the need for its revision. *Disability & Society* 1998 September;13(4):503-23.
- (20) World Health Organization. *Towards a common language for functioning, disability and health; ICF*. Geneva: WHO; 2002.
- (21) Leonardi M, Bickenbach J, Ustun TB, Kostanjsek N, Chatterji S. The definition of disability: what is in a name? *Lancet* 2006 October 7;368(9543):1219-21.
- (22) Perenboom RJM, Chorus AMJ. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 2003 June 3;25(11-2):577-87.
- (23) Van Brakel WH, Anderson AM, Mutatkar RK, Bakirtzief Z, Nicholls PG, Raju MS et al. The Participation Scale: Measuring a key concept in public health. *Disability and Rehabilitation* 2006 February;28(4):193-203.
- (24) Chen HF, Cohn ES. Social participation for children with developmental coordination disorder: conceptual, evaluation and intervention considerations. *Physical Occupational Therapy and Pediatrics* 2003;23(4):61-78.
- (25) Heinemann AW, Tulskey D, Dijkers M, Brown M, Magasi S, Gordon W et al. Issues in participation measurement in research and clinical applications. *Archives of Physical and Medical Rehabilitation* 2010 September;91(9 Suppl):S72-S76.
- (26) Magasi S, Post MW. A comparative review of contemporary participation measures' psychometric properties and content coverage. *Archives of Physical and Medical Rehabilitation* 2010 September;91(9 Suppl):S17-S28.
- (27) Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation* 2008;30(19):1445-60.

- (28) Noonan VK, Kopec JA, Noreau L, Singer J, Dvorak MF. A review of participation instruments based on the International Classification of Functioning, Disability and Health. *Disability and Rehabilitation* 2009;31(23):1883-901.
- (29) Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical and Medical Rehabilitation* 2009 November;90(11 Suppl):S22-S35.
- (30) Fougereyrollas P, Cloutier R, Bergeron J, Cotá J, St-Michel G. *The Disability Creation Process, The Quebec Classification*. Québec: International Network on the DCP; 1999.
- (31) Noreau L, Fougereyrollas P, Vincent C. The LIFE-H: Assessment of the quality of social participation. *Technology and Disability* 2002;14:113-8.
- (32) World Health Organization. *World report on disability*. Geneva: WHO; 2011.
- (33) Dijkers MP, Yavuzer G, Ergin S, Weitzenkamp D, Whiteneck GG. A tale of two countries: environmental impacts on social participation after spinal cord injury. *Spinal Cord* 2002 July;40(7):351-62.
- (34) Misajon R, Manderson L, Pallant JF, Omar Z, Bennett E, Rahim RB. Impact, distress and HRQoL among Malaysian men and women with a mobility impairment. *Health and Quality Life Outcomes* 2006;4:95.
- (35) Pichaimuthu R, Ramaswamy P, Bikash K, Joseph R. A measurement of the stigma among vitiligo and psoriasis patients in India. *Indian Journal of Dermatology Venereology & Leprology* 2011 May;77(3):300-6.
- (36) Boku N, Lockwood DNJ, Balagon MV, Pardillo FEF, Maghanoy AA, Mallari IB et al. Impacts of the diagnosis of leprosy and of visible impairments amongst people affected by leprosy in Cebu, the Philippines. *Leprosy Review* 2010 June;81(2):111-20.
- (37) Rensen C, Bandyopadhyay S, Gopal PK, Van Brakel WH. Measuring leprosy-related stigma - a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation* 2010 August 7;33(9):711-9.
- (38) Slim FJ, van Schie CH, Keukenkamp R, Faber WR, Nollet F. Effects of Impairments on Activities and Participation in People Affected by Leprosy in the Netherlands. *Journal of Rehabilitation Medicine* 2010 June;42(6):536-43.
- (39) Nagata KK. Gender and disability in the Arab region: the challenges in the new millenium. *Asia Pacific Disability Rehabilitation Journal* 2003;14:10-7.
- (40) Rao I. Equity to women with disabilities in India. *CBR Network* . 2004. 15-8-2011.  
Ref Type: Internet Communication
- (41) Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. *Psychology Health and Medicine* 2006 August;11(3):277-87.

- (42) ILEP. Guidelines to reduce stigma; what is health-related stigma? London; Amsterdam: The International Federation of Anti-Leprosy Associations; Netherlands Leprosy Relief; 2011. Report No.: 1.
- (43) Goffman E. Stigma: Notes on the management of spoiled identity. New Jersey: Prentice-Hall; 1963.
- (44) Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Social Science and Medicine* 2010 December;71(12):2150-61.
- (45) Corrigan PW. The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice* 1998;5(2):201-22.
- (46) Corrigan PW, Watson AC, Barr L. The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology* 2006 October;25(8):875-84.
- (47) Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology* 2001;27:363-85.
- (48) Scambler G. Stigma and disease: changing paradigms. *Lancet* 1998 September 26;352(9133):1054-5.
- (49) de Stigter DH, de Geus L, Heynders ML. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Leprosy Review* 2000 December;71(4):492-8.
- (50) Dodor EA, Neal K, Kelly S. An exploration of the causes of tuberculosis stigma in an urban district in Ghana. *International Journal of Tuberculosis and Lung Disease* 2008 September;12(9):1048-54.
- (51) Myint T, Thet AT, Htoon MT, Win M. A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships. *Indian Journal of Leprosy* 1992 July;64(3):313-24.
- (52) Rao PS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and correlates of leprosy stigma in rural India. *Indian Journal of Leprosy* 2008 April;80(2):167-74.
- (53) Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* 2009 January 31;373(9661):408-15.
- (54) Atre S, Kudale A, Morankar S, Gosoni D, Weiss MG. Gender and community views of stigma and tuberculosis in rural Maharashtra, India. *Global Public Health* 2011;6(1):56-71.
- (55) Malcolm A, Aggleton P, Bronfman M, Galvão J, Mane P, Verrall J. HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health* 1998;8(4):347-70.

- (56) Berisha M, Zheki V, Zadzhmi D, Gashi S, Hokha R, Begoli I. Level of knowledge regarding tuberculosis and stigma among patients suffering from tuberculosis. *Georgian Medical News* 2009 January;(166):89-93.
- (57) Rafferty J. Curing the stigma of leprosy. *Lepr Rev* 2005 June;76(2):119-26.
- (58) Nyblade, L, Pande, R, Mathur, S, MacQuarri, K, Kidd, R, Banteyerga, H, Kidanu, A, Kilonzo, G, Mbwambo, J, and Bond, V. *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*. Washington DC: International Centre for Research on Women; 2003.
- (59) Bonjour MA, Montagne M, Zambrano M, Molina G, Lippuner C, Wadskier FG et al. Determinants of late disease-stage presentation at diagnosis of HIV infection in Venezuela: a case-case comparison. *AIDS Research and Therapy* 2008;5:6.
- (60) Gosoni GD, Ganapathy S, Kemp J, Auer C, Somma D, Karim F et al. Gender and socio-cultural determinants of delay to diagnosis of TB in Bangladesh, India and Malawi. *International Journal of Tuberculosis and Lung Disease* 2008 July;12(7):848-55.
- (61) Kalichman SC, Simbayi LC. HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexual Transmitted Infections* 2003 December;79(6):442-7.
- (62) Kalichman SC, Rompa D. HIV treatment adherence and unprotected sex practices in people receiving antiretroviral therapy. *Sexual Transmitted Infections* 2003 February;79(1):59-61.
- (63) Peretti-Watel P, Spire B, Pierret J, Lert F, Obadia Y. Management of HIV-related stigma and adherence to HAART: evidence from a large representative sample of outpatients attending French hospitals (ANRS-EN12-VESPA 2003). *AIDS Care* 2006 April;18(3):254-61.
- (64) Weiser S, Wolfe W, Bangsberg D, Thior I, Gilbert P, Makhema J et al. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome* 2003 November 1;34(3):281-8.
- (65) Corrigan P, Kerr A, Knudsen L. The stigma of mental illness: explanatory models and methods for change. *Applied & Preventive Psychology* 2005;11(3):179-90.
- (66) Dinos S, Stevens S, Serfaty M, Weich S, King M. Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *British Journal of Psychiatry* 2004 February;184:176-81.
- (67) Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science and Medicine* 2007 May;64(9):1823-31.
- (68) Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Services Research* 2010 March 25;10.

- (69) Kilinc S, Campbell C. "It shouldn't be something that's evil, it should be talked about": A phenomenological approach to epilepsy and stigma. *Seizure-European Journal of Epilepsy* 2009 December;18(10):665-71.
- (70) Stutterheim SE, Bos AER, Shiripinda I, de Bruin M, Pryor JB, Schaalma HP. HIV-related stigma in African and Afro-Caribbean communities in the Netherlands: Manifestations, consequences and coping. *Psychology and Health* 2011.
- (71) Weiss MG, Doongaji DR, Siddhartha S, Wypij D, Pathare S, Bhatawdekar M et al. The Explanatory Model Interview Catalog (Emic) - Contribution to Cross-Cultural Research Methods from A Study of Leprosy and Mental-Health. *British Journal of Psychiatry* 1992 June;160:819-30.
- (72) Kelle U. Combining qualitative and quantitative methods in research practice: purposes and advantages. *Qualitative Research in Psychology* 2006;3(4):293-311.
- (73) Cardol M, de Haan RJ, van den Bos GAM, de Jong BA, de Groot IJM. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clinical Rehabilitation* 1999 October;13(5):411-9.
- (74) Ritsher JB, Otilingam PG, Grajales M. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research* 2003 November 1;121(1):31-49.
- (75) Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health* 2001 December;24(6):518-29.
- (76) Kelders R, van BW, Beise K, Irwanto. Testing and validating a simplified scale to measure social participation of people with disabilities in Indonesia. *Disability and Rehabilitation* 2011 October 12.
- (77) Ebenso B, Fashona A, Ayuba M, Idah M, Adeyemi G, S-Fada S. Impact of socio-economic rehabilitation on leprosy stigma in Northern Nigeria: findings of a retrospective study. *Asia Pacific Disability Rehabilitation Journal* 2007;18(2):98-119.
- (78) Nardi SMT, Paschoal JAA, Zanetta DMT. Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Leprosy Review* 2011;82:55-64.
- (79) Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS* 2008 August;22 Suppl 2:S67-S79.
- (80) World Health Organization. *Today's challenges*. Geneva: WHO; 2003.
- (81) Disabled World. *World Facts and Statistics on Disabilities and Disability issues*. <http://www.disabled-world.com/disability/statistics/> 2011;

- (82) Peden, M, McGee, K, and Sharma, G. The Injury Chartbook: A graphical Overview of the Global Burden of Injuries. Geneva: WHO; 2002.
- (83) Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology* 2010 July;63(7):737-45.
- (84) Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. *BMC Medical Research Methodology* 2010;10:22.
- (85) Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of Life Research* 2010 May;19(4):539-49.
- (86) Terwee CB, Mokkink LB, Knol DL, Ostelo RW, Bouter LM, de Vet HC. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of Life Research* 2011 July 6.
- (87) Herdman M, FoxRushby J, Badia X. 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. *Quality of Life Research* 1997 April;6(3):237-47.
- (88) Berry JW, Poortinga YH, Segall MH, Dasen PR. *Cross-Cultural Psychology: Research and Applications*. Cambridge, UK: Cambridge University Press; 1992.
- (89) Brouwers C, Van Brakel WH, Cornielje H, Pokhrel P, Dhakal KP, Banstola N. Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in south-east Nepal. *Disability, CBR and inclusive development* 2011;22(1):16-34.
- (90) van der Zee CH, Priesterbach AR, van der Dussen L, Kap A, Schepers VPM, Visser-Meily JMA et al. Reproducibility of Three Self-Report Participation Measures: the ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Journal of Rehabilitation Medicine* 2010 September;42(8):752-7.
- (91) Bowden A, Fox-Rushby JA. A systematic and critical review of the process of translation and adaptation of generic health-related quality of life measures in Africa, Asia, Eastern Europe, the Middle East, South America. *Social Science and Medicine* 2003 October;57(7):1289-306.

**Appendix 1:** the Participation Scale (v.6.0) (van Brakel et al. 2006)

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

No	Participation Scale	Not specified	Yes	Sometimes	No	Don't want to	No problem	Small	Medium	Large	SCORE
		9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0			0			
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
11	Do you visit other people in the community as often as other people do?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it for you?						1	2	3	5	
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
13	In your village / neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
16	Do you help other people (e.g. neighbours, friends or relatives)?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
17	Are you comfortable meeting new people?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	

No	Participation Scale	Not specified	Yes	Sometimes	No	Don't want to	No problem	Small	Medium	Large	SCORE
		18	Do you feel confident to try to learn new things?		0			0			
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	

Comment:

<b>TOTAL</b>
--------------

Name: \_\_\_\_\_

Age: \_\_\_\_ Gender: \_\_\_\_

Interviewer: \_\_\_\_\_

Date of interview: \_\_\_\_ / \_\_\_\_ / \_\_\_\_