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'Overcoming Disabling Barriers: Perceptions of People Affected by Leprosy in Four Indonesian Self-help Groups'

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Acknowledgments

Abstract

This study looks at the impact of self-help groups (SHGs) of people affected by leprosy in Indonesia. SHGs of disabled people in low-income countries are a medium to advance the economic, social and psychological self-empowerment of their members, aiming at improved quality of life. People affected by leprosy still today often form their own impairment-specific SHGs, mainly as a result of conventional segregating approaches in leprosy.

The objective of this study was to explore perceptions of people affected by leprosy about their membership in SHGs. Various aspects were explored, namely, interaction with peers, self-care activities, income generation, collective action and issues around single- versus multi-impairment groups. A deeper understanding of these issues, so my hope, may become a small contribution to support the development of SHGs oriented on the actual needs of disabled people.

The research for this study was carried out by a team that included three persons affected by leprosy. To equalise the relationship with participants and, with their insight, balance my Western, non-disabled perspective, the three disabled researchers were involved in design, data collection, and analysis of findings. To, ideally, enable participants to openly express their opinions, qualitative data collection methods were applied. Repeated discussions and confirmation of our conclusions may

hopefully have contributed to an enhanced awareness of team members and participants.

Findings of this study show, that, from the participants' point of view, SHGs have a positive impact on the empowerment of people affected by leprosy in Indonesia. Of particular importance appears to be self-management and peer to peer support within the groups; equally significant are the facilitation and encouragement provided by DPOs, guiding the members towards increased consciousness about their abilities and rights. When these preconditions are met, SHGs apparently have good prospects of accomplishing a variety of other activities that may lead to favourable economic and psychosocial developments:

- Next to income generation –which, expectedly, plays a central role– participants perceived collective action as especially rewarding, supporting empowerment and self-assurance.

- Preventing deterioration of impairments through self-care, on the other hand, tends to be neglected and requires motivation, ideally by DPOs.

- Inclusion into multi-impairment groups was endorsed by all participants, and thus might constitute the future ideal model of SHGs.

A main conclusion of this study, consequently, is the need to understand and acknowledge the importance of genuine participation and self-determination of disabled persons as group members, and of DPOs as facilitators in SHGs.

Contents

Abbreviations

CBR	Community based rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO(s)	Disabled People Organisation(s)
FGD(s)	Focus group discussion(s)
HIV/AIDS	Human immunodeficiency virus infection / Acquired immunodeficiency syndrome
ICF	International Classification of Functioning, Disability and Health
IGA	Income generating activities
I/NGO(s)	International / non-government organisation(s)
Loc.	(Research) Location
MFI	Microfinance institute
SHG(s)	Self-help group(s)
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

1. Introduction

"*I think, no human being is perfect, why, then, should I despair? My condition, although maybe I have some deficits, it has become my quality*" (Bapak Kus, Location 2)

Self-help groups (SHGs) in low-income countries are a popular tool aiming at assisting marginalised persons in their social and economic empowerment. This approach is, too, increasingly used with people affected by leprosy. For this study, a team involving disabled people has attempted to explore and understand how people affected by leprosy in Indonesia perceive their membership in SHGs, and how it assists them in overcoming barriers. It is hoped that the study's results may provide information for further enhancement of this approach as a tool to promote inclusion in society. This first chapter will describe the setting of the study, leading into research questions, aims and objectives. It will outline its composition and introduce relevant terminology.

1.1. Background

The Republic of Indonesia is with over 17,000 islands the world's 15th largest, and with a population of 238 Million people its fourth most populous country. Its people belong to a wide diversity of ethnical

groups; 86% of the Indonesians are Muslim. The official national language, Indonesian, is spoken by a large majority, but often not as their first language. 13.3% of the population lives under the national poverty line (BPS, 2010; CIA, 2012).

The number of disabled persons in Indonesia lies between two and 33 Million, varying with the definition of disability and method of survey used (Irwanto, 2010). Roughly 100.000 people amongst them are living with impairments due to leprosy (Firmansyah, 2008). The rights of disabled people in Indonesia are regulated by Law No.4/1997 on People with Disability (hukumonline, 2012); the Convention on the Rights of Persons with Disabilities (CRPD) has been ratified in 2011 (DPR RI, 2011). Implementation of these laws, however, is insufficient (Sunarman, 2010; Haryanto, 2012).

Leprosy, a bacterial infection, is a poverty disease, occurring most often amongst indigent people, with Indonesia ranking third globally in the number of yearly reported cases (WHO, 2009). People affected by leprosy who have been cured are often "burden[ed] due to the physical, mental and socioeconomic consequences of the disease" (*ibid.*: 3). While impairments could often be prevented with timely attention, psychosocial and economic problems ensue as consequences of stigma and discrimination in society (Calcraft, 2006). Where in former times people

infected by the disease were isolated from society (Gould, 2005), treatment is nowadays, in most countries, and including Indonesia, integrated into communal health centres (SCRI, 2010). However, people affected by leprosy still do not have access to many services, and often are excluded by their communities or prefer to isolate themselves, thus entering a vicious circle of poverty and disability (Endang, 2004; NLR, 2009).

A rights-based perspective on disability, calling for the protection of basic freedoms through legislation (Quinn, 2002), has been influential also for the approach towards people affected by leprosy. On this basis, many national and international non-government organisations (I/NGOs) working in the field of leprosy, in Indonesia and elsewhere, have made it their goal to strive for inclusion of people affected by leprosy in all parts of life, promoting their self-empowerment as a central theme (e.g., NLR, 2011; SMHF, 2012). Through self-empowerment, so the idea, people will be enabled to assume their right of equal participation with increased self-esteem (WHO, 2010).

SHGs are thought to be one way to achieve this aim (*ibid.*; Thomas, 2004), where through mutual support people may realise their potential and are enabled to act on it. In Indonesia, with around 20 mostly single-impairment SHGs of people affected by leprosy, this approach is only at

a beginning. SHGs, here, typically develop from self-care groups –i.e., groups focusing on prevention of (further) impairment through simple, home-based measures (NLCP, 2006)– often facilitated by health staff (EJLCP, 2012). Intending to allow for more genuine participation of disabled people, I/NGOs and the Indonesian Leprosy Control Program support Disabled People Organisations (DPOs) as facilitators of SHGs; however, their coverage is still small: Only one DPO of people affected by leprosy exists in Indonesia, operating in three of 33 provinces (PerMaTa, 2012). The Indonesian SHGs commonly focus on income generating activities (IGA). Self-care activities are usually suggested by health staff, while advocacy becomes an additional element when DPO guidance is available. To foster inclusion, the idea of multi-impairment groups has recently been promoted, replacing the exclusive single-impairment groups of people affected by leprosy (Sunarman, 2011).

The impact of SHGs has been evaluated in some countries, showing that economic and social participation tends to increase through this approach (Cross, 2005; Langen, 2012). For Indonesia, such studies are yet lacking. It is, in particular, unclear which aspects of SHGs, from the viewpoint of their members, contribute to positive results, and what these results are. For I/NGOs operating in the field of leprosy in Indonesia (which, incidentally, is my own line of work) these queries are of strategic

consequence and, hence, are the topic of this study, as detailed in the following.

1.2. Research Questions

Based on the above considerations, this study explores the perception of people affected by leprosy as members of SHGs in Indonesia: How and how far are these groups and their different aspects and activities experienced as helpful to overcome barriers and support members in their empowerment, self-actualisation and inclusion within society?

I, here, attempt to obtain insight into the views of members in four SHGs, guided by the following subsidiary questions:

- What barriers do group members experience in daily life?

- How do members perceive activities characteristic for SHGs in Indonesia, i.e. (after, Golo, 2011; Risdiantol, 2012):

  - Interaction with peers

  - Self-care activities

  - Income generating activities

  - Collective action and self-advocacy

- How do members perceive single-impairment versus multi-impairment group membership?

The purpose of exploring these questions will be described in the following section.

1.3. Aims and Objectives

This study aims to enhance our knowledge about models of SHGs that can contribute to enabling its members to overcome –even remove– barriers put up by society. Distribution of the results to organisations working in leprosy control and in community based 'rehabilitation' (CBR) in Indonesia may make a small contribution to the development of strategies and interventions which take the perspectives and self-defined goals of people affected by leprosy into account.

The present study takes as its basis the social model of disability with its "transformative aim [of] barrier removal and the promotion of disabled people's individual and collective empowerment" (Barnes, 2003: 6). It provides, thus, an alternative mode of approach to disability in a country, Indonesia, that tends to resort to either a medical model of disability – with a focus on the individual person whose impairment needs to be fixed– or the International Classification of Functioning, Disability and Health (ICF), which assents that "problems are external to disabled people", but whose "solutions target individual disabled people" (Oliver, 2004: upg.).

Improved knowledge for service providers, then, is not the only aim of this study. Within the limitations of a short-term research (Mercer, 2002), some immediate gain for the participants should be generated. A promising approach can be the participatory involvement of disabled people in the research process, who thereby may develop enhanced consciousness about their lives, barriers and rights (Finkelstein, 1992: 3, cited in Bailey, 2004: upg.). In this study participation, hence, has been the core intention in all stages of the process. As described below, people affected by leprosy were key members in the research team. They were able to create a peer relationship with the participants, thereby equalising the usual top-down hierarchy between researcher and 'subject'. For researchers and participants this may have contributed to their development in obtaining what Oliver (2004: upg.) calls 'citizenship' of empowered individuals.

I sincerely hope that this research may be part of the on-going developments towards enhancement of SHGs as a tool owned by people affected by leprosy to facilitate their own inclusion into society.

In the following an overview of the organisation of this study will be given.

1.4. Composition of the Study

After this general introduction, the second chapter outlines the context of this study. It provides background on disability in low-income countries, and describes barriers often faced by people affected by leprosy; it, too, attempts an overview on current strategies for 'rehabilitation', and of SHGs as a medium for interventions.

The third chapter discusses methodology and methods of this study, and my ethical considerations. It will describe the process of knowledge production by the research team and participants, and the difficulties met with.

The next chapters describe the results of the interviewing and analysis process and relate them to findings in the existing body of knowledge, attempting to engender answers on the research questions: Chapter 4 evolves around barriers experienced by the participants; chapter 5 and 6 cover their opinions on and perceived impact of different aspects of SHGs, i.e., interaction with peers and self-care activities (chapter 5), and IGA, collective action and issues concerning single- versus multi-impairment groups (chapter 6).

The concluding chapter summarises the results, relating them to the main aim on how SHGs, as a vehicle to support people affected by leprosy in their self-empowerment and to advance their inclusion in

society, can be improved. It will, furthermore, outline the limitations of this study.

1.5. Terminology employed

- 'People affected by leprosy' is the terminology promoted by the DPO IDEA (2009) and adopted by main stakeholders as, e.g., the World Health Organisation (WHO, 2011).

- 'Rehabilitation' will be written within quotation marks throughout the text to remind the reader that the concept of correcting an individual person's medical, social or economic problems to become 'normal' is not always in line with what disabled persons need and want (Finkelstein, 1984). It, rather, could be argued that providing equal opportunities in society may solve many a problem, especially as these have been created by society in the first place.

- Impairment and disability will be used as defined by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976, distinguishing between physical impairment –which can be difficult for individuals, but are normal in any given population (Miller, 2006: 42)– and disability caused by society.

2. Locating Self-help Groups of People Affected by Leprosy in Literature

To better understand the meaning of SHGs to people affected by leprosy in Indonesia, I will here outline some relevant contextual factors, and summarise findings from other studies. First, I will review models and meaning of disability in low-income countries; secondly, look at barriers faced by people affected by leprosy and current strategies for their 'rehabilitation'; and finally, examine SHGs and their roles in different settings.

2.1. Disability in Low-income Countries

"In former times we were simply dealing with leprosy patients", a Nepalese doctor recently stated, "now the same clientele are called 'people affected by leprosy'" (pers. comm.). This shift in approach to leprosy from a purely medical to a more holistic and rights-based view, reflected in, e.g., expert journals like 'Leprosy Review' (www.leprahealthinaction.org), is part of worldwide developments, since the 1990s gaining momentum in low-income countries (Hurst, 2006; Albert, 2006a). It is evident –albeit not always acted upon– in policies of I/NGOs and governments, e.g., Indonesia's ratification of the CRPD. The 'bio-psychosocial' disability model of the ICF is commonly employed as

underlying concept of this new approach (Eide, 2008; Nawir, 2009). It defines disability as an umbrella term encompassing impairment, activity and participation, while recognising (not prioritising) the influence of contextual factors (WHO, 2002). Alongside, purely medical models – locating the problem with the disabled person (Hunt, 1966)– are still widespread, as, e.g., described by Kaplan-Myrth (2001) or Yeo (2003).

The social model of disability, first developed by the UPIAS (1976a) and defining disability as caused by "social restrictions imposed upon [disabled people] by society" (Oliver, 1986: 6), is less frequently discussed in all its consequences both in and for low-income countries. While, according to Sheldon (2005), it can provide a basis for radical change of society in these countries, in practice it is more often translated as a rights-based approach (e.g., Hossain, 2003). A rights-based approach only, however, aiming at equal participation of disabled people in "the existing system [that] is the cause of the problem" (Yeo, 2005: 4), is regarded insufficient to obtain real societal change (Sheldon, 2005). Furthermore, it seldom leads to immediate and noticeable improvements of the lives of disabled people (Cornielje, 2009).

On the other hand, the social model of disability, too, is criticised (and wrongly so – see UPIAS, 1976b: upg.) that it, in the face of unmet basic needs of disabled people in low-income countries, allegedly "ignores the

reality of what impairment means for disabled people" (discussed by Hurst, 2006: 27; Finkelstein, 1996; Shakespeare, 1997). There certainly is not one answer to the complex problems of disabled people in low-income countries. Impairment often only becomes a central problem to people because of a disabling environment. Barrett (2005), e.g., describes how stigma (see discussion below) can lead to self-neglect and self-injury, and Calcraft (2006) reports on people losing their job due to reduced physical capability in a society incapable to offer alternative work. In many of these studies, though, the role and responsibility of society is inadequately illustrated.

Barriers and needs of the majority of disabled people are defined by poverty, evolving around access to fundamental provisions like food, shelter and care (Yeo, 2005). The vicious circle of poverty and disability, leading into profound disempowerment, is detailed amongst others by Yeo (*ibid.*) and Elwan (1999). Stone (1996) and Sheldon (2010) call attention to the structural injustices underlying this circle. Although disability is not mentioned in the Millennium Development Goals, it has been acknowledged that to successfully alleviate poverty, disabled people –argued from a rights-based perspective, but also due to their sheer numbers– need to be included in their implementation (UN, 2009).

Disability is furthermore influenced by cultural characteristics. These have been described for low-income countries by, e.g., Ingstad (1995) and Miles (1996) and for Indonesia by Dreezens-Furke (1991). According to Groce (1999), attitudes towards people with impairments depend on beliefs about their causality, valued and devalued attributes, and the expected future of the concerned person. The inability to contribute to family and community, observes Ingstad (2001), often is a vital criteria for 'disability', and it, therefore, becomes a strong desire for many disabled persons to change this situation (cf. Gilson, 2000).

In the following I will discuss the validity of these issues for people affected by leprosy, who, within the group of disabled people, have been "historically overlooked" by many service providers (WHO, 2010: booklet 7: 1).

2.2. People Affected by Leprosy in Low-income Countries

This section will outline barriers faced by people affected by leprosy and describe how society has tried to deal with this group of disabled people during time. I, then, will attempt to give an overview of main current approaches.

2.2.1. Barriers

The WHO's current global strategy for leprosy control programs (2009) sees the main burden for affected people in both impairments and stigma. Arguably, main barriers are rather poverty and stigma: Impairments are often preventable would people not, e.g., hide early signs to avoid stigmatisation (ILEP, 2001). They may deteriorate when access to medical services is restricted due to insufficient coverage of affordable services or refused admission (ILEP, 2006). Resulting activity limitations easily lead into economic difficulties (Ebenso, 2009b). As a rule, due to insufficient social security nets in low-income countries (Irwanto, 2010), these are not averted, and may be further aggravated by rejection at work and avoidance by neighbours and community, leading into social and economic exclusion (Calcraft, 2006).

Stigma, in former models seen as a disgracing physical characteristic (Weiss, 2004: 6), is nowadays considered a social process, first described as such by Goffman (1963), who realised the influence of society in separating 'deviation' from 'normality'. Linked to the possession of power (Link and Phelan, 2006), there are two sides to stigma: those who stigmatise, and those who are stigmatised. While the first may enact stigma –or discriminate–, justify it or accept when others do so, the latter may experience, or feel stigma. Felt stigma refers to the

fear or anticipation of enacted stigma, which "also encompasses a feeling of shame", or self-stigma (Scambler, 1986: 33; Weiss, 2008). As a consequence, stigmatised persons frequently experience exclusion and psychological problems (*ibid.*).

Stigma may be motivated by a perceived violation of norms (Ryan, 2010), and thus doubt about a person's morality and value (Smith, 2007). Reidpath (2005) argues that stigma and social exclusion is a prime mechanism for managing resources through the principle of reciprocal exchange: Those who appear unable to 'give back' are labelled unworthy and excluded from this exchange, justified by blaming them of "moral failure […] before looking to socio-structural causes" (*ibid.*: 475).

Since ancient times, leprosy is connoted negatively (Gould, 2005; for Christianity see Bible, Exodus 13:44; for Islam see Prophetic Traditions by al-Bukhārī, 9th AD). Cross (2006: 369) argues that traditional belief systems mysteriously marked people as being different, having painless wounds and 'supernatural' disfigurement. Next to the fear of contagion, Miles (2000: 606) reminds us of "the human response […] of strong revulsion", referring to severe impairment. Policies, moreover, can cause stigma when, e.g., people affected by leprosy are treated separately from others (ILEP, 2011).

Recent studies in Indonesia found felt stigma amongst people affected by leprosy being more prominent than enacted stigma (Brakel, 2011). Cross (2006, citing Valencia, 1989) reasons that people affected by leprosy regard themselves as sick even after cure, and thus as deviant - they "learn to become lepers" (*ibid.*: 371). Barrett (2005: 222) quotes a person in his study: "'In our society, people hate anyone with this disease'. [The person] insisted that the problem did not lie with his village, but rather with himself". The role and influence of service providers in this situation will be topic of the following section.

2.2.2. 'Rehabilitating' people affected by leprosy

The history of leprosy and how society dealt with it is well described by, e.g., Frist (2003), Gould (2005), and for Indonesia by Zuiderhoek (1993). For centuries, segregation of people affected by leprosy was the intervention of choice (Menn, 1996; Iliffe, 1987; Seng, 2008). After the discovery of alleviating treatment in the 1940s, medical 'rehabilitation' received more attention (Parsons, 2011). The introduction of a cure for leprosy in the 1980s, then, started the process of re-integration and social and economic 'rehabilitation' of affected persons (Frist, 2003). Nowadays, attention has shifted further towards community-based inclusive development, i.e., "a right-based development model that

promotes equality and the participation of […] groups that face discrimination and exclusion" (Dixon, undated: 16; cf. WHO, 2010).

To accomplish inclusion, stigma in society needs to be reduced (ILEP, 2011). Empowerment of stigmatised individuals and their active participation in stigma-reducing activities, here, are regarded as effective (Heijnders, 2006). However, understanding stigma as a social construct, Heiijnders (*ibid.*) also warns against putting the burden of activism against stigma on the affected persons alone. Stigma reducing activities aiming at society through, e.g., dissemination of information, though, have so far found to be less effective (Cross, 2006; Wong, 2004). Reidpath (2005) suggests increasing the socio-economic value of stigmatised persons to permit their re-entry into a system of reciprocity. The positive impact of economic empowerment, e.g. through IGA, is, indeed, recognised not only for poverty alleviation, but even more so as enabling people to interact with and contribute to their communities, thereby gaining respect and dignity (ILEP, 1999). People affected by leprosy, finds Velema (2008b: 4), "become an asset rather than a burden". IGA are regarded –albeit not without criticism– particularly successful within SHGs (ILEP, 1999).

2.3. Self-help Groups

The following section will discuss objectives and issues in different types of SHGs. I will start with the typical SHG of low-income countries and narrow the arguments down to SHGs of disabled persons, and, finally, people affected by leprosy.

2.3.1. SHGs in low-income countries

SHGs, generally, have the purpose of providing opportunity for mutual support through exchange of experiences and knowledge, with an expected outcome of increased self-esteem, self-reliance, and a general 'empowerment' of their members (e.g., Beresford, 1994; Darling, 2003). While in higher-income countries SHGs usually form as therapeutic and support groups (Ahmadi, 2007), the 'typical' SHG in low-income countries has mainly economic objectives, and is an important instrument for poverty alleviation (Deshmukh-Ranadive, 2004).

Microfinance through SHGs became famous with the Bangladeshi Grameen Bank. Its founder Yunus (1998) portrays his philosophy as to provide microcredits to poor people without collateral, thereby challenging other banks' definition of creditworthiness. Credit discipline is ensured by 'social collateral' instead, e.g., peer pressure in SHGs. Credit, so Yunus (*ibid.*), gives control over resources, leading to

economic and social power. It enables people to start self-employment as the most suitable way of poverty alleviation by involving family units and people's creativity.

In recent years, news about failures of self-employment and people falling into "cycles of debt" (Melik, 2010: 1) led to increasing criticism of this concept. Lack of pre-assessments, preparation and information by unscrupulous microfinance institutes (MFI) are the suspected reasons (Biswas, 2010). Where, on the other hand, microfinance is imbedded in a well-functioning SHG, through empowerment of its members, better results are reported (Parida, 2010). Still, the social and psychological impact of SHGs, e.g., regained self-confidence, is, sometimes, found greater than positive financial outcomes (Sinha, 2006). The prospects of disabled persons in this situation will be topic of the following section.

2.3.2. SHGs of disabled people in low-income countries

Disabled people are not usually found amongst the members of microfinance SHGs, despite efforts to include them in, e.g., the Grameen Bank's "Struggling members' program" (Yunus, 2005). Following Simanowitz (2001), reasons for this are self-exclusion, exclusion by staff of MFI, by other group members, and by design, e.g., discriminating requirements of the MFI.

These types of exclusion, finds Cramm (2008), are least present in SHGs set up by NGOs or DPOs (Jong, 2010; Mersland, undated), who allow for soft loans with low interests and prepare members through training in, e.g., home economics and relevant vocational skills (Cramm, 2008). These SHGs, on the other side, are criticised for not being sustainable as they are not trying to access bank systems (Mersland, undated), and, by accepting soft loans, underpin the assumption that disabled people cannot be held accountable like other people (Klerk, 2008). Some advocates of mainstreaming into MFI claim that disabled people with no prior experience and no resources, additionally facing competition disadvantages because of, e.g., inaccessible markets (Cramm, 2008), should not take part in microfinance at all, since their prospects of success would be meagre (Mersland, undated). Other authors, again, offer creative alternatives, by, e.g., stimulating saving in SHGs as one first step out of poverty, or by negotiating special conditions with MFI to introduce the idea of including 'unreliable' disabled persons as clients (Klerk, 2008).

SHGs of disabled people do often not only aim at economic empowerment, but have important additional objectives when they engage in collective action and advocacy (Hossain, 2003; Dhungana, 2010; Sunarman, 2010), thereby following Finkelstein's (2007) plead for diverse grassroots activities to promote human rights. The "shared

experience of discrimination and exclusion" (Hurst, 2006: 28), particular in multi-impairment SHGs, is seen as advantage in developing consciousness about these rights.

The power of collective action, hence, may be undermined when groups are divided into specific impairment groups (Shakespeare, 2001). Single-impairment SHGs, according to Shakespeare (*ibid.*), have been deliberately promoted by governments aiming to "divide and rule" over disabled persons (*ibid.*: 554). He asserts, however, that these groups may, too, be progressive and beneficial (2006), and Devlieger (2005) gives examples of disability culture based on specific impairment.

Some authors, again, warn that 'disabled identity' in groups –and maybe particularly so in single-impairment groups–, could be disempowering (Galvin, 2003: 676), may lead into isolation instead of inclusion (Gilson, 2000), or that to "continuously reassert the experience of subordination may be just as disempowering as the original experience of discrimination" (Goodley, 1996: 343).

Another issue is that of SHGs initiated and led by health professionals, which may reinforce dependency (Stewart, 1999) and medicalization (Ahmadi, 2007). Many SHGs, nevertheless, have successfully mobilised and won over control to speak for themselves (Shakespeare, 2001).

These arguments may be particularly relevant in regard to people affected by leprosy, who, even amongst disabled persons, often are a group apart (Khasnabis, 2008).

2.3.3. SHGs of people affected by leprosy

While SHGs of disabled people in low-income countries tend to be multi-impairment groups (e.g., Hossain, 2003), people affected by leprosy are frequently separated into single-impairment groups, generated by the historic separation of services. The recently published guidelines on CBR (WHO, 2010) found it necessary to devote a supplementary chapter on HIV/AIDS, mental health and leprosy, stressing that persons affected by these issues should equally be included into CBR programs, DPOs and SHGs. Their inclusion in multi-impairment SHGs is advised in these guidelines, but the case-stories show how rarely, still, this has been achieved (*ibid.*).

Albeit as single-impairment groups, SHGs of people affected by leprosy, nonetheless, are seen as effective instruments to implement current goals of 'rehabilitation', as outlined earlier: SHGs provide a supportive environment for IGA, (ILEP, 1999; WHO/ILEP, 2007), self-advocacy (Cross, 2005; Thomas, 2008; Cornielje, 2008), and the development of self-esteem (Heijnders, 2006; Tsutsumi, 2007; WHO,

2011). Yet, qualitative studies exploring the opinion of people affected by leprosy about these SHGs are rare. Research on their views and needs focuses on medical leprosy services (Dijk, 2003; John, 2005), assesses needs from a purely medical point of view (Gautham, 2011), or employs predominately quantitative methods (Sihombing, 2008; Tonelli-Nardi, 2011). Some authors, hence, appeal to enhance the use of qualitative assessments (Dijk, 2003; Staples, 2011a), and to carefully explore the genuine perspectives of people affected by leprosy (Bonney, 2011; Staples, 2011b).

Three studies were found that focus on the impact of groups from their members' point of view, using mixed quantitative and qualitative methods: Ebenso (2009a) studies self-care groups in Nigeria, Cross (2005) and Langen (2012) both investigate SHGs in Nepal. All three report positive results in, particularly, stigma reduction. Langen (*ibid.*) finds IGA being particularly important for group members, although in this case the initiating NGO had other objectives in mind. Furthermore, she reports multi-impairment groups being preferred by most leprosy affected members, who apparently can profit from the determination of other disabled persons. No study of this kind was found for Indonesia.

2.4. Conclusion

This chapter described the framework around SHGs of people affected by leprosy, by discussing issues of disability in low-income countries, particularly in regard to people affected by leprosy, and SHGs as a vehicle to attain a variety of goals. Next to positive outcomes of SHGs, it mentioned their potential drawbacks. This study attempts to understand the experiences of Indonesian SHGs members with these issues. How participatory research methods were employed to this effect will be topic of the following chapter.

3. Undertaking Participatory Research

This chapter will describe the choice and usage of the research method employed in this study. Its sections will discuss the collaboration with a research team and the process of data generation. Finally, ethical issues for this study will be considered.

3.1. Participatory Research

According to constructivist assumptions, reality does not exist as a fact but is formed through multiple meanings and interpretations (Blaikie, 1993). Internalised social norms, determined by power relations, may influence these interpretations, and result in oppression of those who are not in power (Agger, 1991). It is, however, possible to change these "pieces of history" (*ibid*.: 109), through emancipation and self-reflection (*ibid*.; Blaikie, 1993). Research, aiming at change, should, thus, give the participants a voice, and enable their genuine involvement in inquiries concerning their own lives.

To implement these postulations, participatory research was considered a suitable approach: It seeks the active and comprehensive involvement of participants (Small, 1995), thereby attempting equalisation of power imbalances in research production. Emancipatory research, committed to empower disabled participants by handing over

control, would require a reversion of these relationships (Oliver, 1992). Against the background of Indonesia's hierarchic social structure (Reckinger, 2010a), both disabled people and service providers, including I/NGOs, seem, yet, unprepared to reverse their roles. Participatory research has a long tradition in low-income countries (Small, 1995), and although it may not be suitable to attain far-reaching structural transformations in society (Oliver, 2002a), it can contribute to change on a local level (Balcazar, 2006). This study, still, attempted to realise some principles of emancipatory research, particularly the attainment of gain and a contribution to the empowerment of participants (Oliver, 2002b). The core milestones of this study, hence, can be described as follows:

- Disabled persons presented the majority in the research team, and were involved in design, interviewing, analysis and dissemination of results (Small, 1995), thus balancing my own values as non-disabled European INGO worker (cf. Miles, 1996; Stone, 1997). Particularly during the analysing process they contributed their own genuine understanding and interpretations, thus increasing the significance of knowledge production.

- Interviews were conducted by the disabled researchers, who shared with the participants the experience of living with the consequences of leprosy infection, as well as a similar cultural background and socio-

economic situation (Walsham, 2006). They could, hence, relate in an empathic manner with the participants, encouraging them to express their views openly. Qualitative data generation methods were used to further support participants' ability to voice their perspectives (*ibid.*).

- These open discussions with the participants were experienced as enriching by the disabled researchers. Gain was, thus, obtained in form of increased consciousness of researchers and, possibly, of participants (Mercer, 2004; Campbell-Brown, 2001). Moreover, the disabled team members developed their skills as researchers, which may heighten their chances to obtain similar assignments in future.

- Reflexivity about our interpretations was attempted by reconfirming the results of data generation with the participants (Flick, 2010).

- Service providers and policy makers were and will be directly informed of the research findings, giving people affected by leprosy a clear influence on the design of strategies (Balcazar, 2006).

Research can only inform and ideally influence policies, if it complies with quality criteria. The following values, as suggested by Guba and Lincoln for qualitative research (1994, cited in Mercer and Barnes, 2002), guided this study:

- Credibility of the results was pursued through a sensitive conduct and thorough data recording, including their reconfirmation (Kumar, 2011).

- Dependability of findings –ensuring that process and findings are trustworthy and consistent (Flick, 2010)– was endeavoured by careful preparation of the research team. Consistency between interviewers was attempted by jointly composing the interviewing guide, and by discussing results of each interview during the analysis workshop.

- Conformability to avoid purposeful bias (Kumar, 2011) was attempted through openness about the researchers' background and values, during interviewing and analysis (Campbell-Brown, 2001).

- To maximise its benefit, transferability of the results to other situations has been an aim of this study. Since qualitative research is context-specific, clear accounts of the research situations are given (Annex I), which may enable readers to judge whether results are transferable to their own situation (Kumar, 2011; Flick, 2010).

How these values were set into practice will be described in the following sections.

3.2. Preparations with the Research Team

In the following I will describe study preparations: the setup of a team, development of the interviewing guide and sampling procedures.

The decision to work with a team of disabled people affected by leprosy was an integral part of my commitment to conduct a participatory research. As noted above, a key reason for such a collaboration lay in attaining a more profound understanding through the insider role these persons could take (Flick, 2010).

The team consisted of five persons: three disabled members of local branches of a DPO of people affected by leprosy, my Indonesian colleague in her position as CBR consultant for the same INGO I am employed with, and myself. With two of the disabled persons I had worked before in CBR and research projects, the third, although inexperienced in research, was recommended to me by the DPO. All three had practical experience with SHGs. They agreed to make time for an estimated number of days, for which they received fees. Three persons –not less– were selected to limit the time they would spend away from work and home, and to match language skills with research locations. Due to the great variety of local languages in Indonesia, the latter, however, was only partly successful, eventually leading to communication setbacks during some of the interviews.

The CBR consultant's assistance was required for her good experience in organising field work. My part in the team was to guide us through participatory research. Since I, too, had defined the initial

research question and would write up the end report, my influence in this study was still dominating. It was, also, me, not the team, being responsible for the funds my employer had kindly provided for this study (cf. Barnes, 1997). Much more time and preparation would have been necessary to satisfyingly equalise our relationships (cf. Katsui, 2008; Stone, 1997).

During a preparation workshop, training was conducted, facilitated by the CBR worker and me. We discussed and practiced interviewing skills needed in a qualitative and participatory approach, and talked about features of these methods and about the social model of disability. Due to limited options for field practice, the disabled researchers decided to jointly conduct data collection in the first location, thereby sharing existing experiences with the still inexperienced researcher, who later proved to have a talent for interviewing. All in all, more training in exploring deeper layers of participants' understanding would have been beneficial, which, however, was also hampered by above mentioned language barriers.

During the workshop, an interviewing guide (see Annex IV) for focus group discussions (FGD) and semi-structured interviews (see chapter 3.3.) was developed: Based on the research questions, the disabled researchers suggested and discussed themes for data collection from

their own perspective, assumingly similar to the perspective of the participants. In this process they also adopted a clear understanding of the layers behind the research questions, which later helped them during interviewing.

Sampling of study locations and participants was a further part of the workshop. The sample of SHGs should represent the characteristic activities outlined in the research questions above in diverse but typical settings (Flick, 2010): urban and rural, in 'normal' communities and in leprosy settlements. Since the number of SHGs in Indonesia is small, purposive sampling was employed. This approach allowed us to deliberately select groups with the largest potential of fulfilling these criteria and of advancing our understanding (*ibid.*; Palys, 2008). Where I had envisioned a sample size of three, the disabled team members selected four groups which they found relevant for this study. On purpose we included the only multi-impairment SHG that involves people affected by leprosy. The disadvantage of this purposive selection was that based on our own subjectivity we chose SHGs we regarded as meaningful, thereby ignoring groups with a smaller range of activities, most of which are found in government-led SHGs. Details of the four locations are described in Annex I.

Purposive sampling of typical cases –members who were not unusual or extreme in their socio-economic status or attitude (Flick, 2010)– within the groups was applied to select participants for the interviews, based on criteria set up by the team (Annex II). Gender proportions, as defined beforehand in line with the varying gender proportions of each group, were incorporated.

For FGDs total samples of all group members (in average 20 persons) were used (Flick, 2010), however, in the smaller group of location 2 only eight persons attended due to heavy rain (see overview in Annex III). The process of data production will be discussed in the following.

3.3. Data Generation

This section describes how information was generated, from interviewing to analysing, and difficulties met.

To allow participants to express their views and give room for deeper discussions of specific topics, semi-structured interviews were chosen as data collection tools. Following an interviewing guide ensured that all key issues were covered (Hancock, 2002). Since the interviewers did not have to restrict participants in their answers, they felt comfortable with this method; however, the possibility of prompting interesting aspects with further questions posed a challenge for them. With more training,

even more and deeper information might have been revealed. Interviewing length, thus, varied from two hours to only 20 minutes. The shortest interviews happened in location 3, in Central Java; I assume here the additional influence of the strong Javanese culture of politeness and shame, which usually prevents people from sharing deeper feelings (Fuller-Collins, 2000; Indrawati, 2011).

FGDs were added to verify and add information (Fallon, 2002). They proved to be very valuable in this study, as they provided rich additional insights and an impression of group dynamics. Not all members participated equally: Some were more outspoken than others. My hope was that those who mainly listened still obtained some gain.

Another disadvantage of FGDs lay in the greater organisational effort needed, leading, due to operational difficulties and limited resources, to the decision to omit a FGD in location 3; we, instead, increased the number of interviews in this SHG. This, however, still proved to be unfortunate: While the group was particularly interesting as it was the only multi-impairment SHG of the sample (see Annex I), interviews, as said before, were short in this location. In compensation, during confirmation visits, some additional information was obtained from the disabled facilitators of this SHG.

The disabled researchers conducted 15 interviews (14 were planned, one was spontaneously added in location 4) and three FGDs. After jointly working in the first location, each researcher took charge of one of the three remaining SHGs, which we allocated as best as possible in line with travel distances and language skills. During field work, the interviewers were accompanied by the CBR worker for introduction and organisational matters. She, too, acted as note taker during FGDs, but was not involved in moderating. Neither she nor I were present at interviews, as to not influence the peer relationship mentioned above. I did not join the field visits altogether, anticipating that, as I had experienced before, my appearance as Westerner would create expectations and may distort results (cf. Berghs, 2010). While Stone (1997) rightly argues that sometimes these "sensitivities" are imagined, I, however, felt confirmed in my caution when one of the disabled researchers described his experience: Talking to me, as a Westerner, makes participants proud, while talking with him, as an equally leprosy affected person, "makes them happy and relaxed" (pers. comm.).

All interviews and FGDs were tape-recorded. Detailed transcriptions of these recordings and associated notes were prepared by the respective interviewers, thereby partly translating from local Makassar and Javanese into Indonesian, and fearlessly overcoming limited computer skills. Analysis, then, was conducted by the whole team in a second

workshop: First, the collected data was reviewed and relevant information highlighted, relying much on the insight of the disabled researchers (Hancock, 2002). By means of content analysis (Kumar, 2011), making use of three walls of the meeting room and many cardboard cards, key topics were identified, the information organised under further categories and sub-categories and links established to find patterns and develop theories related to the topics researched (Baptiste, 2001). Care was taken to be reflective about any divergent backgrounds within the team, particularly the DPO influence and my Western way of thinking, and the setting of different SHGs which affected the interpretations (Mauthner, 2003; Campbell-Brown, 2001). As it contributed to new insights in the functioning of SHGs, we all experienced this process as greatly rewarding.

After the workshop, I made a summary of the results, which was confirmed and adjusted by all team members and then used by them for discussions at confirmation visits to the SHGs. Resulting comments and corrections were noted, and it was my task, then, to relate the findings with the existing literature on the topic, and to compose a report in English. Before finalisation, we within the research team discussed the report draft for correction and approval in a final meeting.

As part of the attempt to be accountable towards participants, a dissemination plan of the results was set up jointly. Recipients are a network of I/NGOs, DPOs and the Indonesian Ministries of Health and of Social Affairs. A shorter version of the results in Indonesian language will be provided alongside for effortless access. For the members of the SHGs an additional hand-out with key findings will be produced in their respective local languages (Makassar and Javanese). In the meantime, results were discussed frequently and served as reference in workshops and meetings on related topics.

3.4. Ethics

This study attained ethical clearance from Atma Jaya University, Jakarta, and was guided by the Statement of Ethical Practice of the British Sociological Association (BSA, 2002). Particular attention was paid to preventing this research from reinforcing "subordination of disabled people" (Shakespeare, 1996: upg.; cf. Oliver, 1992). The requirement of writing a dissertation, hence, should not be the only pretext for this study; it rather was my hope to provide a small contribution in improving 'rehabilitation' programs in Indonesia (Flick, 2010). By applying a participatory approach, guided by the social model

of disability, accountability and a sensitive conduct was intended, and, ideally, a direct gain for disabled people envisioned.

After informing them about objectives and methods of the research, their rights, and the opportunity to discuss results during feedback visits, written consent was obtained from all participants (Annex V). Confidentiality was ensured by encrypting their names (Flick, 2010). Expenses for participants were covered and their contributions were rewarded with a small gift. The participants themselves chose times and places for the interviews and group discussions.

3.5. Conclusion

The methodology and methods employed in this research were instrumental to the findings derived from it (Flick, 2010). Information and conclusions as related in the following chapters are to a great extend generated by disabled people, both as participants and as researchers, which, so I hope, reflects insider perspectives and intimate knowledge on the topic of research.

4. Barriers in Peoples' Lives

This study aims to understand how SHG members perceive their groups as helpful in overcoming barriers. In this chapter I will discuss where participants met difficulties as a result of being affected by leprosy. Impairments will be examined first - not to put importance to it, but to confirm the statement of the social model that not impairments but the environment presents a main problem for disabled persons.

Quotations of participants, in the following, are translated. Their names are pseudonyms; *Bapak* refers to male, *Ibu* to female persons. Numbers refer to the locations detailed in Annex III.

4.1. Impairment

"*People here are normally disgusted when they see a person with severe leprosy*" (Bapak Iman, loc.4)

According to the definition of the ICF, impairments are problems in body function or structure (WHO, 2002). Due to nerve-function loss, people affected by leprosy can develop often severe impairments at eyes, hands and feet. For some participants of this study impairments meant that they were physically unable to continue with their former, usually manual, work. Periods of inflammation, a side effect of leprosy caused by the body's immune system (ILEP, 2002), additionally

distressed participants as it led to deterioration of their physical resilience. People feared and had experienced that hard work could prompt new episodes of inflammation. They knew that even stress –such as worries about work– could be a trigger.

Impairments, yet, had another meaning for all participants: It made them recognisable as persons affected by leprosy. Neighbours would say, as a woman explained: "What happened to her, how does she look like? This must be contagious" (Ibu Mawar, loc.4). With increasingly perceived severity of impairment, according to participants, rejection by their environs would increase, as it is likewise documented by, e.g., Sihombing (2008) and Boku (2010).

Despite these concerns, impairments featured only as a minor aspect in the accounts of the participants. One possible explanation is given by Gray (2002): Ignoring the perceived causes of embarrassment could be an attempt to pass as 'normal', an argument that could be linked with the numerous descriptions of self-stigma, detailed below. The particulars of location 1, a leprosy settlement where everybody has extensive impairments acquired during many years of living with the consequences of leprosy infection, but no one even mentioned them once, allows for another explanation similar to the description of poor communities in Mali by Kaplan-Myrth (2001) where impairments became normality in a

setting where everybody had them. Maybe most important, however, is an explanation given by the WHO (2010: booklet 7, p. 37): "Often, it is not the physical impairments or even the functional limitations that cause the greatest problems for people affected by leprosy". The following sections, hence, will address the economic, social and psychological consequences that may follow from living with impairments due to leprosy in an unaccommodating environment.

4.2. Economy

"*Those who don't like me anymore won't give me any work*" (Ibu Indah, loc.2)

Indonesia ranks in a medium field on the Human Development Index (UNDP, 2011), with large parts of the population facing economic difficulties. For all participants, in varying degrees, such problems were part of their daily reality. Some of them could just get along, whereas others lived in bleak poverty. Most participants recounted that their situation had deteriorated after their illness, since they could not continue work as before. Activity limitations forced some to change into more suitable professions, but they faced meagre opportunities due to rejection at work: "Where can you work with a sick foot? Nowhere" (Bapak Slamet, loc.3). For others, avoidance in community had led to a

decrease in their income, particularly –as, too, noted by Velema (2008b) in a study on Asian and African countries– for those who sold food products.

The loss of income had severe impacts on the participants' lives. For some, fulfilling basic needs of their families became a daily struggle. In other cases health care was neglected due to lack of money and affordable access: One person reported, "I couldn't get a new prosthesis, so I had to make one myself" (Bapak Wahyu, loc.3). As elaborated by Elwan (1999) such circumstances would increase the risk of further impairment and, consequently, poverty.

The loss of economic status, too, meant a loss of respect in community. A man was embarrassed about a new job he had to take on, which he perceived as inferior to the former (Bapak Iman, loc.4). He stated that though his family had in fact enough income, he felt an urgent wish to contribute, according to Ingstad (2001), a common concern of disabled people living in similar context. Other participants sensed a loss of acceptance in community as they were unable to live up to cultural demands: A women had to take up a loan to buy a flatiron because she wanted to send her child to school in a neat uniform; others, in more urban areas, could not afford popular products like the ever-present cellular phones. A participant realised: "If I had enough money, it would

not be a problem that I can't walk properly" (Bapak Wahyu, loc.3). This impact of society will be further discussed in the following section.

4.3. Stigma and Discrimination

"*There is always someone who evades me – the neighbours, at work, in the mosque*" (Ibu Indah, loc.2)

As demonstrated above, stigmatising attitudes and discrimination is a common experience for people affected by leprosy. While, tendentially, older participants had to tell the more drastic incidents of discrimination from the past, in the present negative attitudes in society were still felt and experienced: "It certainly cannot be denied that people have a bad feeling about us and, no question, they are afraid and distance themselves from us" (FGD 2).

The participants thought that the reasons for stigma and discrimination were disgust felt about their appearances, their dry skin or wounds, and the fear of contamination. Explanations from other studies, such as the work of supernatural powers (Cross, 2006), moral failure (Reidpath, 2005) or exclusion of unproductive members of society (*ibid.*), were not part of the explanatory models the participants offered.

Family was the one place that by almost all participants was described as supportive and relatively free from stigmatisation. High incidence of

divorces from persons affected by leprosy in Indonesia, as reported by Sihombing (2008), was not confirmed in this study, although during confirmation discussions some participants shared experiences about rejection even within their families, especially before joining a SHG. Generally, family members may be considered as having an important supporting role in the process of reintegration into community.

The other source of support was derived from leprosy workers in local health-centres. In most cases, satisfaction and gratitude was expressed towards these health workers for providing care and personal attention in times perceived as very difficult. This approval was, though, not extended to other parts of the government, e.g., the local social affairs offices, who were, reportedly, unsupportive. Most participants had no access to or information about governmental provisions available to them. Indeed, according to Irwanto (2010) and Reckinger (2010b), most disabled persons in Indonesia are never reached by any social policy program, which is an offence against Indonesian's law No 4/1997 re Persons with Disability (hukumonline, 2012). Many participants, furthermore, had been ill-informed about options for treatment and costs for it at various health providers. Experiences of institutional discrimination had led to resignation, insecurity and diminished self-esteem: "Even now where I have a child, nobody cares about me" (Ibu Indah, loc.2).

Despite several clear accounts of discrimination, frequently the borderline between enacted stigma on the one side, and perceived or anticipated stigma by the participants on the other side (Scambler, 1986, see chapter 2.2.1.), was not well-defined. Restrictions in social participation, so it may seem, was partly interweaved with internalised self-stigma, as will be discussed in the following section.

4.4. Psychosocial Wellbeing

"*We people affected by leprosy have limitations – they stick to us like glue*" (FDG 2)

As widely described, for the example of leprosy by, e.g., Wong (2002) and Tsutsumi (2004), discrimination by society has an impact on a person's psychosocial wellbeing. 'Psychosocial', after Martikainen (2002: 1), denotes the "influence of social factors on an individual's mind or behaviour". Similarly, Reeves (2004) describes the psycho-emotional dimensions of disability as an effect of oppression. For the participants of this study, the perceived or experienced negative reaction of society towards them led to stress, feelings of inferiority and self-stigmatisation. Participants frequently used the Indonesian word '*malu'* – embarrassed. As apparent in many accounts, these feelings were deeply rooted, leading to the anticipation of stigma: "I didn't leave the house because

people surely would have been angry with me" (FDG 2). Alternatively, participants tried to hide their 'mark' to pass as 'normal': "We know we are sick, but when people don't know, they eat together with us" (Ibu Utari, loc.1).

Another consequence, notably, was an attitude of passivity that was expressed by many participants, who seemed to have resigned and accepted their 'God-given fate' with patience. Wong (2002), respectively, finds that Muslims in a study in Nigeria perceived leprosy as God's will which they were prepared to accept (while in Christianity it was rather perceived as God's punishment). Acceptance, according to the psychological approach of Weller and Miller (1977), is the last stage of emotional adjustment towards a distressing change in life.

The accounts in this study, however, were perceived by the interviewers as expressions of hopelessness and surrendering to 'society', being unable to take back control over the own life. We can find the idea of control in Link and Phelan (2006), who stress the association of stigma with possession of power: The stigmatised person is without power, or control. Correspondingly, Cattell (2001) describes how fatalism occurs when a person feels helpless and out of control. As a way of coping, participants, consequently, declared, e.g.: "I don't care anymore. Yes, it is troublesome, but I don't care" (Bapak Iman, loc.4). Withdrawal,

passivity and self-stigma may, again, reinforce the assumption in society that people affected by leprosy are incapable of leading normal lives and are burdensome or pitiable (Poestges, 2010).

Finally, some discrepancy was found between study locations. Accounts of stigma and self-stigma were numerous in all sites except location 3, in the province of Central Java, where participants didn't recount many of such experiences or feelings. In an attempt to explain these findings, we could not confirm that they were expressions of low stigma levels in the local communities: Preliminary results of a Health System Research (Martini, 2012) reveal a high intensity of stigma in the same area. Additionally, from the viewpoint of the disabled facilitators of location 3's SHG, feelings of inferiority and shame of group members are very common, although, if compared to the time when the SHG just started, nowadays less severe. The best explanation for the, seemingly, reluctance of participants to share their experiences even with peer-interviewers is the specific cultural characteristic of Central Java to refrain as much as possible from disclosing deeper feelings (see above). More time is needed to explore the issue of stigma in depth with these participants.

4.5. Conclusion

This chapter discussed barriers as perceived by participants. Stigma, felt or enacted, was found to be a key issue for most of them, adding to activity limitations and further reducing the anyhow limited access to services in a low-income country, resulting in social and economic exclusion, and leading to internalised self-stigma and fear of further rejection. At the time of this study, the participants had been members of a SHG for some time already, and often recounted the experience of stigma in its different forms as, to some extent, belonging to the past. Whether and how membership in SHGs was helpful for participants to overcome these barriers will be topic of the following chapters.

5. The Meaning of SHGs to their Members – Part I: Interaction and Self-Care

In Indonesia, SHGs frequently develop from self-care groups. The latter's main focus, i.e. interaction with peers and practicing self-care (NLCP, 2006), is, likewise, part of the various aspects of SHGs. This chapter will examine if and how they contribute in helping group members overcoming the barriers described above.

5.1. Interaction within the Group

"*Things I had ignored about myself, now, within the group, are taken seriously*" (Bapak Slamet, loc.3)

When people cooperate in social networks, social capital in form of support, self-esteem, identity and perceptions of control is produced (Cattell, 2001: 1502). One form of social networking is the participation in organisations, which, so Cattell (*ibid.*), can reinstall hope and optimism. Against the background of Indonesian culture, where social life and reciprocal help are greatly valued (Geertz, 1993; Grootaert, 1999), interaction with like-minded people was highly appreciated by all participants: The prospect of meeting friends provided a reason to leave home, enjoying friendships generated pride and elevated self-esteem, lessening moments of resignation through mutual help and sharing of

distress. The evaluation of interviews and FGDs showed that exchange of experiences increased the participants' problem solving skills, and provided resources to improve their situation in a broad spectrum of areas, particularly in work and health. The positive impact of groups on self-confidence and participation has been similarly described by, e.g., Beresford (1994) and Ahmadi (2007) for higher income countries and by Heijnders (2006) and Parida (2010) for low-income countries.

A group, nevertheless, is a delicate and dynamic construction (cf., e.g., the theory of stages in group development, Tuckman, 1965, cited in Tuckman, 1977), and most participants were aware that building up a strong and well-functioning SHG requires their active participation and commitment. On many occasions they stressed the importance of coherence and unity. Only then would they all benefit in the way they wished, particularly regarding economic ventures (see chapter 6.1.). Passionate discussions during FGDs confirmed the importance of this point: "We own this group. To become better we have to trust each other as friends and work together" (FGD 1).

In order to become unified, so the participants, a group must lay down rules, binding for everyone, to prevent conflicts and create ownership. Evidently, this process was already well on the way, noticeable by the frequent use of the word "we" when talking about mechanisms set up

and actions taken by the group. In FGD 1 a conflict was discussed where a member had disagreed with a decision taken by others without informing him – these and other examples showed that self-set rules within the group created structure and a sense of control: Within the small community of the group, people were able to demand their rights based on these rules. Presumably, this could contribute to their regaining of confidence in taking control and realising their rights in other areas of life.

Rules, furthermore, required that tasks and duties were accepted and taken up with responsibility to keep the group functioning, thereby promoting the feeling of being needed. Duty was oftenest debated when it came to irregularities of attendance at group meetings. Participants argued: "When people say they are busy as an excuse for not attending, our activities will be ruined and fall apart" (FGD 2). Responsibility, here, was offered as a motivation for members to attend regularly. This stands in contrast to the argument of many health workers in Indonesia, that only money –in form of reimbursement for transport– is an effective attraction to make people join groups (frequent pers. comm.; NLCP, 2006). It clearly demonstrates the difference between top-down approaches from authorities and grassroots initiatives building on consciousness.

To develop consciousness, repeated discussions about the merits of SHGs were held within the groups. A young man recounted that "first, I didn't really see the point, but after I got all this information from the others, yes, then I very much agreed to become a member" (Bapak Iman, loc.4). The participants realised and pointed out barriers that hindered some members to attend meetings, foremost due to costs of transportation and income loss when leaving work. But they possessed the will to persevere and offered practical solutions, picking each other up and arranging convenient meeting places and times. Overall, the participants displayed high levels of awareness and commitment to keep the groups alive. While one must be aware about a possible wish of some participants to present in a favourable light (Atkinson, 2005) –we know from monitoring reports about these SHGs that reality is often less perfect (e.g., Risdiantol, 2012)– their accounts revealed their interpretation of the situation: They considered dedication and self-management as a meaningful goal, preferred over remaining in a role of passive recipients.

While participants wished their SHG to become progressively stronger and flourishing and showed ownership and responsibility to achieve this aim, there was, on the other hand, almost no desire to liberate the group from the influence of the health centres (except location 3 where the health centre was not involved). Indeed, as described in chapter 4.3.,

leprosy workers played an important role in the lives of most participants. As related by the disabled researchers, often, former patients feel emotionally attached and in times even obliged to health workers. Participants, hence, had no wish to detach themselves from leprosy workers, but valued their advice and support. While the assistance of these workers should be appreciated, their approach, however, is often a top-down one, as may be seen in accounts like: "I was not told what kind of group meeting it was they wanted me to attend" (FGD 2). Their dominance was further evident in the fact that many participants were under the impression that health workers not only initiated SHGs but also provided necessary funds for microcredits, where in reality local NGOs and DPOs should receive recognition for this.

Indeed, various authors warn against professional-led SHGs fostering dependency (see chapter 2.3.2.). The aim of health workers, unquestionable, is to help, but rarely are they prepared to support self-determination (Pupulin, 2005), which, according to Hurst (2006), is vital for attaining equality. It is common that health workers play a significant role in starting groups (Dhungana, 2010; Velema, 2008a), but later they should, in Werner's words (undated, cited in Albert 2006b: 15), "recognize the right of disabled persons to self-control, and therefore gracefully step to one side". In Indonesia, the support of health workers is valuable –the country has a close-knit system of health centres

reaching even remote areas–, and their assistance in health and self-care is indispensible (SCRI, 2010) and wished for, as we have seen, by the participants. For the role of a SHG's facilitator, however, DPOs may be better suited, as, on an equal basis, they can educate members about their rights and abilities (Pupulin, 2005), and guide them in critically choosing, or leaving, advice from other well-meaning parties. The role of DPOs and health workers in promoting self-care will be a topic of the following section.

5.2. Self-Care

"*My family supports me in practicing self-care; they see the disease declining this way*" (FGD 4)

The importance of impairment prevention is recognized by Abberley (1987: upg.), stating that "the key distinction that must be made is between the prevention of impairment, on the one hand, and attitudes to and treatment of people who are already impaired on the other".

Self-care is an essential and successful measure for people affected by leprosy to prevent and control impairment, particularly ulcers (Ebenso, 2009a). It is supported, e.g., by the Innovative Care for Chronic Conditions Framework (ICCC) of the WHO (Cross, 2007b). Self-care groups have been developed in Indonesia since 1998 (NLCP, 2006) and

often form the basis for further development into SHGs: Three SHGs in this study started this way.

Accordingly, all participants knew self-care methods and believed them to be important in reducing impairments; many shared success stories about closed wounds. There was a general hope to 'heal from leprosy', demonstrating the strong association between impairment and disease, rendering it unimportant –from the participants' viewpoint– that wounds are in fact not directly related to leprosy, from which they were already cured, but to neuropathy (ILEP, 2006). The main benefit, for some participants, was obtained by understanding the manageability of impairments: "I profit for my feet, although they won't entirely heal, but at least the wounds are clean and won't get worse" (Bapak Serang, loc.1), recalling the concept of control over one's own life. Cross (2007a: 59) argues that self-efficacy, a sense of 'I can do it', best describes this aspect of self-care.

Compared to other group activities, though, self-care played a far smaller role in the participants' accounts, and it wasn't described as major part within SHG agendas: "Those with wounds care for these at home; at meetings we only discuss the results" (FGD 2). These findings are consistent with the comparatively lower significance which impairment seems to have for most participants, as discussed in chapter

4.1.. I have argued there that it is not impairments posing the greatest difficulty for many people, but the reaction of society towards them. Consequently, people may see a need to hide their wounds to avoid this reaction, but to a much lesser degree do they perceive the need to prevent or cure these –painless– wounds. We may, therefore, conclude that self-care is not considered overly important or helpful in overcoming barriers.

However, it is useful to look deeper. Being reminded of Abberley (1987, see above), while it is necessary to remove negative attitudes in society, it is also necessary to prevent impairment that otherwise would progressively deteriorate. Referring to Cross (2007b), who has linked low compliance in self-care to low degrees of self-efficacy and self-esteem, we may rather conclude that participants, to some extent, did not yet feel competent to take up control over their wounds, and, even, did not feel worth of it. Self-neglect, as confirmed by Barrett (2005), can be a consequence of low self-worth.

The reason for low self-efficacy, as Cross (2007b) argues further, is that it does not go along well with health structures still common in many low-income countries where medical models are dominant and health workers are regarded as trusted experts. Cross (2007b: 326) refers to Parsons' 'sick role' (1951), where "any challenge to the power structure

[…] is perceived as an influence that destabilises the foundation of [these experts]". Thus, people affected by leprosy have been familiarised with the medical model in order to maintain reliance on professionals (*ibid.*, 2007a: 58). Many participants in this study were introduced to self-care in their former self-care groups through a medical-model approach, not aiming at true self-reliance (NLCP/NLR, 2009). As discussed previously, to affect change, health workers need to become consultants who support people in their self-empowerment. An empowered person, then, will deem it worthwhile to take care of his or her health and manage impairments with responsibility. A successful SHG, the disabled researchers with their advanced awareness due to their DPO background argued, can be recognised by its attention to self-care, thereby expressing self-respect.

5.3. Conclusion

This chapter examined the meaning of basic elements in SHGs: Interaction with peers was perceived as highly rewarding, as friendships were built and mutual help experienced. Likewise appreciated were structure and responsibilities within the group, seemingly helping members to recover confidence, control and purpose, all of these being elements of empowerment (Naraya, 2002). Participants saw the

importance of self-managing their impairments through self-care; however, prevailing low levels of self-worth may be the reason for an, often, lacking compliance. Self-worth and self-efficacy are values which can be supported and promoted in groups, provided that good guidance is available. Given the widespread availability of health workers in Indonesia, it seems worthwhile to prepare them for a role in facilitating SHGs, particularly in promoting self-care. The 'right' mind-set to offer guidance for internal empowerment, on the other hand, seems more readily available in DPOs, as will be further discussed in the following chapter.

6. The Meaning of SHGs to their Members – Part II: Economy, Advocacy and Inclusiveness

The SHGs in this study had a variety of activities on their agenda, including, in one group, gymnastics. Most prominent endeavours were IGA and collective action, the topics of this chapter. I will discuss, too, implications of one important additional element, i.e., the recent promotion of multi-impairment groups inclusive of people affected by leprosy.

6.1. Income Generating Activities

"*We want to show to the community that we can do things just like every other person, although we had leprosy*" (Bapak Kus, loc.2)

As shown in a number of studies (e.g., Velema 2008a; Reidpath, 2005), the social value and power of marginalised persons increases when they are enabled to re-integrate into local economies. This reveals that people affected by leprosy "are less likely to be stigmatised because of impairments than for their incapacity to contribute to family/community" (Ebenso, 2010: 99): With still the same impairment, they now face less discrimination.

Participants in this study, not unexpectedly, highly valued IGA, here mainly savings schemes and loans which they managed independently

within their groups. Most had been able to start or improve their own small businesses, which, for some, was in line with what they felt would allow them to work without risking deterioration of impairments: "This is what we need, work that fits our condition and is less exhausting" (FGD 4). For others, it helped to meet daily needs. Participants, too, reported about regaining acceptance: "Now, they begin to take me as I am, with my condition" (Ibu Indah, loc.2). These accounts on gaining recognition, however, were not directly linked to IGA, rather were they expressed as an overall impact of SHGs. For many, the *idea* of earning sufficient income seemed to have an inspiring effect, triggering hope of money as solution for assorted problems: "In my group we will not give up, although we have these lives, we are these people, but now [with the loans], we can be independent" (Bapak Wahyu, loc.3).

As known from other studies, not always is it possible for SHG members to increase their income through IGA (see chapter 2.3.1. and 2.3.2.). We did not, in this study, inquire about actual profits or losses made –a recent evaluation of location 1 showed 15 members with successful businesses and four with failures in four years; the latter had repaid their loans and were keen on trying again (Hasibuan, 2012)–, but tried to understand what it takes, from the participants' viewpoint, to make IGA successful. The participants themselves identified three aspects required for effective loan- and saving schemes, i.e., (i) the right

personal attitude, (ii) cooperation within the group, and (iii) external support, particularly in form of start-up funds and capacity building:

A responsible, 'right' attitude (i), according to participants' experience, prevents problems with repayments of loans to the group's fund, which usually occur "due to the person's character, not because they can't afford to pay" (Bapak Serang, loc.1). Similarly, Orr and Patient (2005, cited in Cross, 2007b: 327) argue that internal empowerment in form of "positive identity, aspirations and a conviction that life is valuable" is the foundation for IGA. This attitude, so the participants, is still missing in some members, who hope to receive grants "to ease the burden of impairments" (FGD 2), influenced by their experiences with provisions offered by charity-minded organisations and governments without paying attention to internal development of the recipients (Frist, 2003). However, with guidance and positive role models of DPOs, apparently, attitudes can change: "When I met Achmad [a DPO member, name changed], I realised I shouldn't only think of myself but how we as a group can progress" (Bapak Bambang, loc.2).

The general importance of coherence and unity within SHGs (ii) has been discussed in chapter 5.1.; participants considered rules particularly essential when handling microcredits. They were set up by the members, adequate to specific contexts: In location 1, a settlement where people

were used to receive grants from well-meaning donors, a strict system of peer pressure (cf. Yunus, 1998) was applied to enforce regular repayments. "'Pay', we tell them", a woman described, "'we get into trouble just because you don't pay'" (FGD 1). In a group of indigent farmers (location 2), in contrast, weak members were approached with understanding and granted delay for repayments to overcome difficult times, thus allowing inclusion of the most excluded members of society as, e.g., a single mother facing multiple oppression due to her family situation, poverty and disability (cf. Vernon, 1999). In all groups, in fact, voluntary group savings were utilised to support members in need – thereby replacing the lack of governmental support with community-based initiatives.

Three of four SHGs in this study had received start-up money from external sources (iii), which they used to provide low-interest microcredits for their members. Klerk (2008) warns against such subsidies as they would confirm an assumed incapacity of disabled people. Instead, he advocates for access to loans at normal banks. On the other hand, Yeo (2005) cautions against inclusion into a system that in itself is unjust (cf. Yunus, 1998). In SHGs, we may argue, a more humanistic alternative is practiced. Poor and excluded people are able to obtain access to loans, which, in line with Simanowitz's findings (2001, see chapter 2.3.2.), they would fail to obtain at banks: "If you don't have

anything, you can't get a bank loan. But in the group, it's easy; it's for the common people" (Bapak Tri, loc.3).

Members of the SHGs have been able to increase their income with very small credits, some only amounting to 20$, because their peers would provide additional assistance, e.g., repairing a motorbike. Given the opportunity to make a first step out of exclusion and poverty, they were enabled to access other provisions from the local government. Arguably, they have not been entirely dependent beforehand, nor were they entirely independent afterwards. In this study, nevertheless, the facilitation of start-up funds by external sources appeared useful and justified as a stepping-stone in a process of self-empowerment. At the same time, it should be the task of DPOs, governments and I/NGOs, to promote fairer conditions at banks, thus making mainstreaming not only possible but also desirable.

Finally, the opportunity of a stepping-stone would be missed without capacity (Wehmeyer, 2000: 113). Most participants were enthusiastic about learning new skills, offered by local NGOs in cooperation with local government, thus enhancing their resources (Cattell, 2001). "I never knew how to sew", said an elderly woman, "now I can produce these clothes" (Ibu Sita, loc.1). Not everybody, though, was able to join adequate training, for which participants were still willing to take the

blame: "Some can't join because their hands don't function properly" (FGD 1). Apparently, the way to offering 'reasonable accommodations' (CRPD, 2006) by service providers was still far, thus, the risk of IGA failing due to a lack of capacity (Klerk, 2008) still imminent.

With the participants perceiving IGA as beneficial, it is interesting to consider whether SHGs would still be attractive for them without this option. "I did not join because of loans", said a participant, "in the beginning it was about discussing the value of life and being together" (Bapak Slamet, loc.3). However, other participants argued that becoming an independent group requires its members to have resources at least to leave work for meetings (Bapak Wahyu, loc.3; FGD 2). Similar findings are made by Langen (2012) at SHGs in Nepal, favouring IGA despite the donor-NGO's different objectives. This may illustrate priorities SHG members in low-income countries have, whereas, according to Werner (1998, cited in Hurst 2006: 27), disability activists in higher-income countries may be easier able to focus on their fight for social rights.

6.2. Collective Action

"*I can meet and tell people that what they always assumed is bad about me, in fact is not true*" (FDG 2)

A way to express empowerment, according to Beresford (undated, cited in Hanley, 2005: 15), is collective action. Unexpectedly, most participants in this study were involved in various forms of activism and self-advocacy, something they, moreover, perceived as very rewarding: They began to develop self-confidence to face society and their own fear of it. They felt, furthermore, that their activities had an impact – people in their communities began to change their attitudes. These accounts, hence, confirm theories in stigma research, where through active involvement of stigmatised persons satisfying results in stigma-reduction can be achieved (see chapter 2.2.2.).

Types of collective action in the SHGs varied. A common form was the yearly celebrations of international days of disability and of leprosy. Participants expressed how for their very first time they had entered a hotel, how they overcame their embarrassment and felt like 'normal' people: "It makes us happy and excited – we, with leprosy, we meet other people with leprosy, and we meet normal people" (Bapak Bambang, loc.2). Hurst (2006: 32) describes the process of becoming aware of ones rights as "through a prosaic route, people simply trying to

understand the oppression they experience". Similarly, participants reported how they realised what leprosy means for them and for others, and how they started talking about this to non-disabled people. Not always was this 'prosaic' process immediate: Some participants mainly remembered the transportation money they had received to join an event. To the majority, however, participation in these events bestowed pride, motivation and a reason "not to give in" (Ibu Wulan, loc.3).

Another opportunity for self-advocacy, likewise enriching for all sides, was given when non-disabled persons –doctors or social workers– conducted study visits to the SHGs. "They came to learn from us, it was extraordinary", described a participant. As a NGO worker, I tend to look critically upon these visits where external professionals seem to intrude. The participants, in contrast, welcomed the fact that these people sat with them, listened and for a moment abandoned hierarchical barriers. The attention produced through these visits, moreover, contributed in making the SHGs and their activities widely known in their communities, thus challenging the negative image of leprosy and its "passive victims" (Poestges, 2010: 165).

A small number of participants took the challenge and engaged in even more proficient forms of advocacy, e.g., speaking at village meetings or in schools, disseminating information about leprosy to

"reduce the negativity that is around us" (FGD 2), and experiencing at the same time a rapid increase in self-confidence. Crucial in encouraging participants to join any of these activities, thereby giving the groups a deeper meaning, were DPOs. When, according to Cattell (2001: 1512), "deprivation can be both a cause of hopelessness and a spur to social action", DPOs greatly contributed in turning the wheel towards the latter.

Collective Action, however, can be potentially risky. Goodley (1996) sees a danger for disabled persons when reiterating the experience of stigmatisation, reinforcing the image of pitiful sufferers. This may indeed be the case when people not yet look upon themselves as right-holders, but as victims or "wounded identities" (Davis, 1998, cited in Galvin, 2003: 677). To overcome such an attitude, guidance by DPOs, again, seems essential. Others argue that disability identity, through, e.g., group membership, may reinforce exclusion (Galvin, 2003; Gilson, 2000). Participants of this study did not express this concern; instead they felt that common identity gave them the necessary courage to join events with 'normal' people.

Dube (2006) reports repercussions from governments as a consequence of disability activism in Asia and Africa. The Indonesian participants, instead, voiced more subtle problems: At advocacy visits to school classes, teachers would demonstrate lack of interest by leaving

the room (FGD 1), or in village advocacy meetings governmental staff would occasionally demand payment for their attendance (FGD 4 and 1). Facing lack of support, the participants insisted they would not give in but try even harder.

They would do this, however, in what, to them, is a culturally appropriate way: "We want a relationship of mutual support with the local government – therefore we have to cooperate" (FGD 2). The disabled researchers further elaborated that it is necessary to accept the government's way of working, although it seems obstructive in times; activism would bear no risks as long as all stakeholders are involved in a correct manner. Direct confrontation would not be regarded an acceptable method in Indonesian culture, where polite cooperation is the way to achieve change, albeit slow. Far-reaching changes in society demanded by, e.g., Finkelstein (2007) or Sheldon (2005), may be hard to attain through this approach. However, it is necessary to accept the pace of grassroots DPOs and SHGs: As suggested widely, disabled people need to be the key actors in developing awareness (e.g., Oliver, 1996; Flood, 2005).

Finally, we found a difference in the level of interest in collective action between the three SHGs of people affected by leprosy –where eagerness was high– versus the multi-impairment group, where

participants were comparatively indifferent. While we could not entirely clarify the cause for this discrepancy, and may explain it with the above mentioned cultural inclination to avoid expressions of feelings, it led to further deliberations on the benefits of single- versus multi-impairment groups, which will be discussed in the following section.

6.3. Single- and Multi-Impairment SHGs

"*I'm happy to be with the others. Everybody knows different things to solve our problems*" (Bapak Tri, loc.3)

As a remnant of separated treatment and interventions in leprosy, multi-impairment SHGs including people affected by leprosy are rare in Indonesia (cf. Cornielje, 2009). The SHG of location 3 is one exception. While, thus, being only hypothetically considered in the three single-impairment SHGs, the perspectives of the participants about mixed groups in location 3 were based on real experiences.

In the latter SHG we interviewed only members affected by leprosy. All participants claimed that they felt content being a part of this group, no one mentioned discriminative attitudes from peers with other impairments. While some participants were indifferent about the topic, most of them preferred having friends with different backgrounds and experiences, offering a wide spectrum of solutions. This correlates with

findings from Langen (2012) in Nepalese multi-impairment SHGs where leprosy affected members profited from other disabled persons who were more active. By and large, participants seemed to identify less with 'leprosy' than with 'disability': "There are disabled members in the group – also leprosy affected ones – at any rate, we are disabled" (Ibu Wulan, loc.3). While all participants in the single-impairment groups saw themselves as people affected by leprosy, one (of five) participant(s) in this location expressly termed himself a 'person with disability', as introduced by the facilitating DPO. These findings can be seen as, albeit small, positive developments towards the inclusion of people affected by leprosy within the broader field of disability.

In the single-impairment groups, all participants without exception thought it a very good idea to join with other disabled people. While in the preparation meeting for this study some researchers had predicted that group members would be reluctant to share their benefits, this did not materialise. On the contrary, participants hoped they would gain insight from a greater variety of members, and thought it enjoyable to share: "I would want to exchange my experiences with them, divide my luck, my fortune" (Ibu Sita, loc.1). Others, again, envisaged additional members as fellow activists to advocate their cause. Only few participants were slightly less confident and doubted that other disabled persons wanted to join them, but would feel ever so pleased if they did:

"That would mean they acknowledge that we are of benefit for others" (Bapak Eko, loc.4).

On the other hand, none of the participants in these single-impairment SHGs felt excluded in the groups as they were, but considered them an opportunity to meet 'their' peers: "We can share how it feels to have leprosy – the disease, treatment, work" (Bapak Arif, loc.4). Similar experiences are described for other impairment-specific SHGs (e.g., Delbrück, 2007). Indeed, according to Cattell (2001), homogeneous groups promote understanding and support; however, dissimilar groups provide access to a wider range of resources, resulting in greater benefits for all (see chapter 2.3.2.).

The question is, then, whether people affected by leprosy gain more from developing a common identity with similarly affected peers, or from developing awareness about issues they have in common with other disabled people (Shakespeare, 2001). As mentioned above, there were signs that participants in the multi-impairment group showed less enthusiasm to engage in self-advocacy, compared to peers in the single-impairment groups who were eager to spread information about leprosy. We may argue that, since the single-impairment groups were guided by a DPO of people affected by leprosy towards overcoming 'leprosy-typical' barriers, such as strong self-stigma, their members felt

particularly addressed and encouraged to participate in collective action (cf. Gilson, 2000: 211).

While this may be seen as an advantage, single-impairment groups, on the other hand, underline the exclusiveness of people affected by leprosy and undermine equality with other disabled persons. A disabled facilitator of the multi-impairment SHG drew a comparison with inclusive education: While there are advantages of being in a group with people having special needs, in an inclusive group people affected by leprosy will learn not to identify themselves as 'special' and exceptionally stigmatised, but will become aware of the wider scope of denied rights and experience the advantages of struggling together (cf., e.g., Barton, 1997).

Nonetheless, equal participation of people affected by leprosy in a group of other disabled people who –possibly– are more confident, should be guaranteed through careful guidance by a DPO. Similarly to Flood (2005: 185), who warns that mainstreaming may result in disability issues dropping off the agenda of development organisations, the issues some persons affected by leprosy face, especially due to often profound feelings of inferiority, should not be ignored by simply 'integrating' leprosy into 'disability'.

6.4. Conclusion

This chapter explored how participants perceived the impact of IGA and self-advocacy. Widely, participants favoured IGA as a main activity in SHGs, hoping and experiencing that increased income helps to reduce poverty and social exclusion. They acknowledged that a set of rules and a ready attitude is indispensable for success: self-responsibility and leaving behind an image of passive victims. While it was not unexpected that participants approved IGA, it was more surprising that most of them found it likewise important to engage in collective action. Activism, for them, did not mean to outspokenly demand their rights, but to realise their equality with non-disabled people and their ability to face an adverse environment, thereby achieving change in the immediate environment and for themselves.

Finally, this chapter looked into the benefits of multi-impairment versus single-impairments groups. The idea of multi-impairment SHGs was welcomed by all participants without exception, expecting that this form of SHG can strengthen members in their ability to overcome shared barriers. Development of multi-impairment SHGs should therefore be high a priority for support organisations as a step towards inclusion of people affected by leprosy. In the same time, attention should be paid to ensure equal participation and self-actualisation of people affected by

leprosy in inclusive SHGs. The guidance by DPOs proved to be of great advantage for all aspects in SHGs, since, as positive role-models, they can advance awareness and self-empowerment.

7. Final Conclusions

In the following I attempt to summarise findings of this study, beginning with an overall conclusion, followed by an overview of different aspects in SHGs, and, finally, policy implications. However, limitations of this study will be pointed out first.

7.1. Limitations

Before drawing conclusions, it is necessary to outline some of the limitations this study faced. The sample size of four SHGs gave a good insight into diverse settings; to allow a better comparison with the single-impairment SHGs, however, the multi-impairment group should have been more deeply explored. Since Indonesia has a great potential to utilise health workers for assisting SHGs (providing they are well trained), it would, too, have been enriching to include groups facilitated not by DPOs but by health workers. Interviews and FGDs were conducted by the disabled researchers, who did an excellent job. With time for more intensive training, however, even better results might have been achieved. Communication with participants was, in addition, in some cases hampered by language barriers, resulting from budget and time restraints to train more researchers speaking relevant local languages.

Transferability of findings may be limited to SHGs in the context of leprosy in Indonesia and, maybe, other Asian countries. Wider research for groups of persons with other 'types' of impairments, and in other countries, would be valuable.

Despite these limitations, useful information was produced, related in the following.

7.2. The Meaning of SHGs to their Members

This study had the aim of exploring whether SHGs can assist their members in overcoming barriers. The participants identified these barriers primarily in the fields of economic and social participation, resulting from perceived or experienced stigma in society. These discriminations had a negative psychological impact on almost all participants, mainly in form of self-stigmatisation. Additionally, they had to deal with activity limitations due to impairments in the context of an often adverse environment.

To overcome these barriers, the key impact of SHGs lay in the participants' self-empowerment: They regained confidence and developed determination to improve their lives. Empowerment, Naraya (2002) similarly finds, is predominantly defined by having access and control over assets, choices and outcomes. Many of the participants

showed a high level of awareness about the nature of their problems and had realised that these were not caused through their own fault, but by their environment. They recognized their own crucial role in changing this situation:

> "If we think we are worth nothing and don't go anywhere because we are so ashamed of ourselves, the other people will believe that this is the truth, that we are worth nothing. But if we brave ourselves, go out to them, sooner or later they will see what we can do, and they will question themselves" (FGD 2).

Change in their environment, as perceived by the participants, had set in: Non-disabled people were less inclined to avoid them, more often accepted them in their midst, and regarded them "as human beings" (FGD 1). Seen against the backdrop of deep-seated negative attitudes about disability in society, which are difficult to change (Hurst, 2006; Miller, 2006), these are valuable steps towards a more inclusive society. In attaining this outcome, the different aspects and activities in SHGs mutually interplayed, influencing each other.

7.3. The Meaning of different Activities in SHGs

It appears that not a single activity or aspect in SHGs, but only their combination affected the impact of self-empowerment described above.

Evidently, however, the aspects explored in this study had specific meanings for the participants:

- Social interactions within the groups appeared to be the greatest immediate benefit felt by the participants. By interacting with peers and jointly keeping the group functioning, they regained self-worth and developed determination, which, presumably, influences other areas of their lives, and may result in easier access and participation within the economic and social life of their communities. Guidance by DPO members greatly contributed to this process, as they helped to increase the group members' awareness about their situation.

- Self-care measures to prevent further impairments, according to the participants, furthered their 'healing' process from leprosy. By discounting the fact that the disease itself was already cured, the participants demonstrated how closely they associated the negatively charged 'leprosy' with their impairments. By reducing impairments, particularly wounds, they thought to prevent stigmatisation by others. Nevertheless, participants did not consider self-care as of high importance, tending to ignore and hide instead of assuming control, which was interpreted as lack of self-efficacy and self-worth. With further increase of self-esteem, e.g. within SHGs, so the conclusion, self-care may gain importance in the eyes of group members. This,

again, will need the guidance of facilitators able and willing to promote empowerment.

- The opportunity to escape poverty through IGA featured as an important theme in all accounts. Participants of this study who had started small enterprises had successfully used this opportunity as a stepping-stone to improve their lives, thereby defying criticism about subsidised microcredits (Klerk, 2008). Success, vitally, was facilitated through group support. Other essential preconditions were guidance, ideally by other disabled persons, a responsible attitude, and external assistance in form of, e.g., training. Within this setting, IGA, seemingly, can be very helpful to overcome barriers of poverty and social exclusion. Sustainable –but fair– solutions replacing subsidised funding from I/NGOs and government, need to be explored.

- Despite the economic hardships they experienced, most participants appreciated spending time on collective action and advocacy. By taking part in events they realised that it was possible for them to see new places and meet new people, and that they were able to correct assumptions of others about their 'condition'. Most forms of activism were inspired by DPOs. All activities were designed in line with cultural demands for politeness and harmony; nonetheless, according to participants, signs of attitude changes in their environment were already perceivable, thus confirming, e.g., Heijnders' (2006) and

Cross' (2006) opinion that active participation of stigmatised persons is effective in stigma-reduction.

- Finally, multi-impairment groups were seen as an opportunity for enhanced mutual learning and strengthening of groups. Slightly lesser identification with 'leprosy' in the one multi-impairment group gives hope that this approach, indeed, leads towards inclusion of people affected by leprosy within the broader field of disability. The less spirited engagement in self-advocacy of participants in the multi-impairment SHG gives rise to the notion that attention to individuals or groups of persons with specific needs within multi-impairment groups may still be required to ensure their equal participation. This might be especially important for people with issues that tend to be left behind, like, e.g., leprosy (WHO, 2010).

Summarising, these findings suggest the overall importance of interaction and support amongst peers, facilitated by persons who are able to promote empowerment. These, ideally, should be other disabled persons who share common issues with the members and are able to guide them in developing awareness. Within such a setting, activities like IGA and advocacy, even self-care, have good prospects of affording positive outcomes for the members in form of further emancipation and increased participation in communities. Multi-impairment groups, supposedly, significantly contribute to these effects and add momentum

to the advancement of inclusion. To overcome conventional single-impairment concepts of service providers, active encouragement and reinforcement by DPOs, I/NGOs and governments is required, as suggested in the following.

7.4. Policy Implications

Thomas (2004: 46) some years ago stated that "it is yet unclear what kind of rehabilitation is most acceptable to leprosy affected people", mentioning SHGs as one important option. This study confirmed that in the context of Indonesia, SHGs are widely accepted by their members, rendering their further expansion advisable. I/NGOs and government can contribute in making them successful.

The agenda within a SHG should, undoubtedly, be decided upon by its members, in so doing creating ownership. It seems prudent, however, to offer and provide guidance and assistance in, e.g., developing critical consciousness in the beginning phase. The question of who should provide this assistance is a delicate one. In Indonesia, health workers may play an important role due to their usually good relationship with people affected by leprosy. However, they need to make a shift from charity- and medical model approaches towards promoting empowerment, thereby surrendering control. The four study groups

benefited considerably from guidance by DPOs, who have –rather than health workers– a justification to advise other disabled persons on their lives. For I/NGOs or governments, this implies to acknowledge the importance of DPOs and to support their expansion and consolidation. Besides, there is a need to prepare health workers to take on an adequate assisting role in the facilitation of SHGs, e.g., in areas where no DPO is active yet, and in situations where members have medical needs.

The participants' positive assessment of collective action should prompt I/NGOs and governments to give room to self-advocacy by disabled persons through, e.g., their participation in strategic (governmental) meetings and events where their voice should be heard. Importantly, the expansion of multi-impairment SHGs should be promoted, replacing exclusive groups of people affected by leprosy. As participants showed determination to develop potent (multi-impairment) groups in interaction with communities, their contributions to community development programs should be encouraged and supported. This proved successful in, e.g., Nepalese projects where disabled people became change agents in their communities, advancing the process of transformation of attitude towards disabled persons in society (Cross, 2005).

Finally, needs for further research became apparent, particularly on (i) multi-impairment SHGs with people affected by leprosy, on (ii) the influence of cultural factors –in Central Java in this study– when conducting research, and on (iii) the effect of self-advocacy by people affected by leprosy on their communities, if seen from the perceptive of non-disabled people.

Bibliography

ABBERLEY, P. 1987. The Concept of Oppression and the Development of a Social

    Theory of Disability. *Disability, Handicap and Society*, 2, 5-19.

AGGER, B. 1991. Critical Theory, Poststructuralism, Postmodernism: Their

    Sociological Relevance. *Annual Review of Sociology*, 17.

AHMADI, K. 2007. *What is a Self Help Group*. Psych Central

    (http://psychcentral.com/lib/2007/ what-is-a-self-help-group/all/1/) Accessed 7

    November 2011

ALBERT, B., HARRISON, M 2006a. Lessons from the Disability Knowledge and

    Research Programme. In: ALBERT, B. (ed.) *In or out of the mainstream?*

    Lessons from research on disability and development cooperation. Leeds:

    The Disability Press.

ALBERT, B., HARRISON, M 2006b. Changing the Social Relations of Research -

    managing a disability research programme. In: ALBERT, B. (ed.) *In or out of*

    the mainstream? Lessons from research on disability and development

    cooperation. Leeds: The Disability Press.

AL-BUKHĀRĪ .Tib, 19

ATKINSON, P. 2005. Qualitative Research - Unity and diversity. *Forum Qualitative*

    Social Research, 6.

BAILEY, K. 2004. Learning more from the Social Model: linking experience,

    participation and knowledge production. In: BARNERS, C., MERCER, G.

    (ed.) *Implementing the Social Model of Disability: Theory and research.*

    Leeds: The Disability Press.

BALCAZAR, F., et al. 2006. *Participatory Action Research and People with Disabilities: Principles and challenges.* (http://home.interlog.com/-krogh/Krogh/Pg105.html) Accessed 20 April 2011

BAPTISTE, I. 2001. Qualitative Data Analysis: Common Phases, Strategic Differences. *Forum: Qualitative Social Research*, 2.

BARNES, C. 1997. Breaking the Mould? An introduction to doing disability research. In: BARNERS, C., MERCER, G. (ed.) *Doing Disability Research.* Leeds: The Disability Press.

BARNES, C. 2003. What a Difference a Decade Makes: Reflections on doing 'emancipatory' disability research. *Disability & Society*, 18.

BARRETT, R. 2005. Self-Mortification and the Stigma of Leprosy in Northern India. *Medical Anthropology Quarterly* 19.

BARTON, L. 1997. The Politics of Special Educational Needs In: BARTON, L., OLIVER, M. (ed.) *Disability Studies: Past Present and Future.* Leeds: The Disability Press

BERESFORD, P., CAMPBELL, J. 1994. Disabled People, Service Users, user Involvement and Representation. *Disability & Society,* 9.

BERGHS, M. 2010. Coming to terms with inequality and exploitation in an African state: research in disability in Sierra Leone. *Disability & Society*, 25.

BIBLE. Exodus 13:44

BISWAS, S. 2010. *India's micro-finance suicide epidemic.* Medak, Andhra Pradesh (www.bbc.co.uk/news/world-South-Asia-11997571)

BLAIKIE, N. 1993. Introduction. *Approaches to Social Enquiry.* Cambridge: Polity Press.

BOKU, N., et al. 2010. Impacts of the diagnosis of leprosy and of visible impairments amongst people affected by leprosy in Cebu, the Philippines. *Leprosy Review,* 81.

BONNEY, J. 2011. Responding to the socio-economic implications of leprosy. *Leprosy Review*, 82.

BPS 2010. (Badan Pusat Statistik) Statistics Indonesia: Poverty. Jakarta. (http://www.bps.go.id/) Accessed 15 June 2012

BRAKEL, V. W. 2011. *Preliminary findings baseline study SARI Project.* Jakarta: UI-Indonesia-and-VU-Amsterdam.

BSA 2002. (British Sociological Association) *Statement of Ethical Practice for the British Sociological Association.* Durham: British Sociological Association.

CALCRAFT, J. H. 2006. The effects of the stigma of leprosy on the income generation of leprosy affected people in the Terai area of south-east Nepal. *Asia Pacific Disability Rehabilitation Journal,* 17.

CAMPBELL-BROWN, S. 2001. Methodological Paradigms That Shape Disability Research. In: ALBRECHT, G., ET AL. (ed.) *Handbook of Disability Studies.* London: Sage.

CATTELL, V. 2001. Poor people, poor places, and poor health: the mediating role of social networks and social capital. *Social Science & Medicine*, 52.

CIA. 2012. (Central Intelligence Agency) *The World Factbook - Indonesia* (https://www.cia.gov/library/publications/the-world-factbook/geos/id.html) Accessed 6 June 2012

CORNIELJE, H., et al. 2008. Inclusion of persons affected by leprosy in CBR-Workshop report. *Leprosy Review*, 79.

CORNIELJE, H. 2009. The Role and Position of Disabled People's Organizations in Community Based Rehabilitation: Balancing between dividing lines. *Asia Pacific Disability Rehabilitation Journal,* 20.

CRAMM, J., FINKENFLUEGEL, H. 2008. Exclusion of disabled people from microcredit in Africa and Asia: a literature study. *Asia Pacific Disability Rehabilitation Journal*, 19.

CROSS, H. 2005. *STEP Evaluation Report.* American Leprosy Missions.

CROSS, H. 2006. Interventions to address the stigma associated with leprosy: A perspective on the issues. *Psychology, Health & Medicine,* 11.

CROSS, H. 2007a. A focus on the issues associated with implementing self-care as an intervention. *Leprosy Review*, 78.

CROSS, H. 2007b. The prevention of disability for people affected by leprosy: whose attitude needs to change? *Leprosy Review*, 78.

CRPD, 2006. (Convention on the Rights of Persons with Disabilities) (http://www2.ohchr.org /english/law/disabilities-convention.htm) Accessed May 2012

DARLING, R. 2003. Toward a Model of Changing Disability Identities: A proposed typology and research agenda. *Disability & Society,* 18.

DAVIS, L. J. 1998. Who put the 'The' in the novel? Identity politics and disability in novel studies. *Novel* 31.

DELBRÜCK, H. 2007. *Rehabilitation and Palliation of Cancer Patients*, Paris, Springer.

DESHMUKH-RANADIVE, J. 2004. *Women's Self-Help Groups in Andhra Pradesh. Participatory Poverty Alleviation in Action.* Scaling Up Poverty Reduction: A Global Learning Process and Conference Shanghai: World Bank.

DEVLIEGER, P. J. 2005. *Generating a cultural model of disability.* 19th Congress of the European Federation of Associations of Teachers of the Deaf (FEAPDA).

DHUNGANA, B. M., KUSAKABE, K. 2010. The role of self-help groups in empowering disabled women: a case study in Kathmandu Valley, Nepal. *Development in Practice,* 20.

DIJK VAN, M., VISSCHEDIJK, J., KWAAK VAN DER, A. 2003. 'Client satisfaction' - guidelines for assessing the quality of leprosy services from the clients' perspective. *Leprosy Review*, 74.

DIXON, undated. A Guidance Paper for an Inclusive Local Development Policy.

DPR-RI 2011. (Dewan Perwakilan Rakyat) Pengesahan Konvensi mengenai hak-hak penyandang disabilitas, DPR RI

DREEZENS-FUHRKE, J. 1991. Kesawanan - Zum Traditionellen Verhalten bei Kinderkrankheiten auf Java. *Curare,* 14.

DUBE, T., et al. 2006. Promoting Inclusion? Disabled people, legislation and public policy. In: ALBERT, B. (ed.) *In and out of the mainstream? Lessons from research on disability and development cooperation.* Leeds: The Disability Press.

EBENSO, J., et al. 2009a. Self-care groups and Ulcer prevention in Okegbala, Nigeria. *Leprosy Review*, 80.

EBENSO, J., VELEMA, J. 2009b. Test-Retest Reliability of the Screening Activity Limitation and Safety Awareness (SALSA) Scale in North-West Nigeria. *Leprosy Review*, 80.

EBENSO, B., et al. 2010. 'Money is the vehicle of interaction': Insight into social integration of people affected by leprosy in Northern Nigeria. *Leprosy Review,* 81.

EIDE, A. H., et al. 2008. Exploring ICF components in a survey among Xhosa speakers in Eastern & Western Cape, South Africa. *Disability & Rehabilitation,* 30.

EJLCP 2012. (East Java Leprosy Control Program) KPD Grati, Pasuruan

ELWAN, A. 1999. Poverty and Disability, A Survey of the Literature. *Social Protection Unit, Human Development Network, The World Bank.* Washington.

ENDANG, WIDJIARTINI & BEISE, K. 2004. *The Quality of Leprosy Services from the Clients' Perspective - East Java Province Indonesia*, 2004. Jakarta: Netherlands Leprosy Relief.

FALLON, G. 2002. Focusing on focus groups: lessons from a research project involving a Bangladeshi community. *Qualitative Research*, 2.

FINKELSTEIN, V. 1984. Rehabilitation Services. In: LOBSTEIN, T.; Namibia-Support-Committee-Health-Collective (ed.) *Namibia: Reclaiming the Peoples Health*. AON Publications.

FINKELSTEIN, V. 1992. *Researching Disability: setting the agenda for change*, National Conference, June.
(http://www.leeds.ac.ukldisabilitvstudies/archiveuklindex.html.)

FINKELSTEIN, V. 1996. Outside, 'Inside Out'. *Coalition.*

FINKELSTEIN, V. 2007. *The 'Social Model of Disability' and the Disability Movement*

FIRMANSYAH, A. 2008. *Self-Care Groups in the Leprosy Control Program in Indonesia*. MA, Royal Tropical Institute.

FLICK, U. 2010. *An Introduction to Qualitative Research*, New Delhi, Sage Publications India.

FLOOD, T. 2005. 'Food' or 'Thought'? The Social Model and the Majority World. In: BARNES, C., MERCER, G. (ed.) *The Social Model of Disability: Europe and the majority world*. Leeds: The Disability Press.

FRIST, T. 2003. *Don't treat me like I have leprosy,* London, ILEP.

FULLER-COLLINS, E., BAHAR, E. 2000. To know Shame - Malu and its Uses in Malay Societies. *An Interdisciplinary Journal of Southeast Asian Studies*, 14.

GALVIN, R. 2003. The Paradox of Disability Culture: The need to combine versus the imperative to let go. *Disability & Society*, 18.

GAUTHAM, M. S., et al. 2011. Community-based needs assessment of Leprosy patients in Chamrajanagar District, Karnataka, India. *Leprosy Review*, 82.

GEERTZ, C. 1993. *The Interpretation of Cultures*, London, Fontana

GILSON, S., DEPOY, E. 2000. Multiculturalism and Disability: A critical perspective. Disability & Society, 15.

GOFFMAN, E. 1963. *Stigma: Notes on the Management of Spoiled Identity,* Englewood Cliffs, NJ, Prentice Hall.

GOLO, P. 2011. *Kelompok Perawatan Diri (KPD) Jongaya*. NLR

GOODLEY, D. 1996. Tales of Hidden Lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society*, 11.

GOULD, T. 2005. *Don't fence me in,* London, Bloomsbury.

GRAY, D. E. 2002. 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness,* 24.

GROCE, N. E. 1999. Disability in cross-cultural perspective: rethinking disability. *Lancet,* 354.

GROOTAERT, C. 1999. *Social Capital, Household Welfare and Poverty in Indonesia.* The World Bank.

GUBA, E. G., LINCOLN, Y. S. 1994. Competing paradigms in qualitative research. In: DENZIN, N. K., LINCOLN, Y. S. (ed.) *The Handbook of Qualitative Research.* Thousand Oaks, California: Sage.

HANCOCK, B. 2002. *Trent Focus for Research and Development in Primary Health Care: An Introduction to Qualitative Research.* Trent Focus

HANLEY, B. 2005. *Research as empowerment*? Report of a series of seminars organised by the Toronto Group. York: JRF.

HARYANTO, U., RACHMAN, A. 2012. Indonesian Businesses Don't Want to Risk Hiring The Disabled. *Jakarta Globe*, 6 June 2012

HASIBUAN, Y. 2012. *Evaluasi keberhasilan KUK Jongaya*, Makassar. Jakarta. NLR.

HEIJNDERS, M., MEIJ VAN DER, S. 2006. The fight against stigma. An overview of stigma reduction strategies and interventions. *Psychology, Health & Medicine,* 11.

HOSSAIN, M. 2003. *The Self Help Organizations of Disabled People: "A Voice of Our Own*". ADD, Bangladesh.

HUKUMONLINE. 2012.

(Http://www.hukumonline.com/pusatdata/detail/416/node/20/uu-no-4-tahun-1997-penyandang-cacat) Assessed 9 June 2012

HUNT, P. 1966. A Critical Condition. *In:* HUNT, P. (ed.) *Stigma: The Experience of Disability* London: Chapman, G.

HURST, R., ALBERT, B. 2006. The social model of disability, human rights and development cooperation. In: ALBERT, B. (ed.) *In and out of the mainstream? Lessons from research on disability and development cooperation.* Leeds: The Disability Press.

IDEA 2009. (International Association for Integration Dignity and Economic Advancement) *The Oral History Project. Terminology: The Importance of Language in Promoting Dignity* (http://www.idealeprosydignity.org) Accessed 25 March 2012

ILEP 1999. (International Federation of Anti-Leprosy Associations) *Guidelines for the social and economic rehabilitation of people affected by leprosy,* London, ILEP.

ILEP 2001. (International Federation of Anti-Leprosy Associations) *How to Diagnose and Treat Leprosy*, London.

ILEP 2002. (International Federation of Anti-Leprosy Associations) *How to Recognise and Manage Leprosy Reactions*, London.

ILEP 2006. (International Federation of Anti-Leprosy Associations) *How to Prevent Disability in Leprosy,* London.

ILEP 2011. (International Federation of Anti-Leprosy Associations) *Guidelines to reduce stigma,* London, ILEP, NLR.

ILIFFE, J. 1987. *The African poor: a history*, Cambridge University Press.

INDRAWATI 2011. Politeness in Community Practice. *Journal of Language and Literature*, 5.

INGSTAD, B. 1995. Mpho ya Modimo - A gift from God: Perspectives on "Attitudes" towards Disabled Persons. *In:* INSTAD, B., WHYTE, S. R. (ed.) *Disability and Culture.* Berkeley: University of California Press.

INGSTAD, B. 2001. Disability in the Developing World. In: ALBRECHT, G., ET AL. (ed.) *Handbook of Disability Studies.* London: Sage.

IRWANTO, I., et al.. 2010. *Analysis On The Situation Of People With Disability In Indonesia: A Desk Review.* Jakarta: Centre For Disability Studies, University of Indonesia.

JOHN, A., KUMAR, D.V. 2005. Patients' perceptions of reconstructive surgery in leprosy. *Leprosy Review*, 76.

JONG, D. M. 2010. *Microfinance for People With Disability.* Master, De Vu.

KAPLAN-MYRTH, N. 2001. Blindness Prevention in Mali: Are Improvements in Sight? *Disability Studies Quarterly,* 21.

KATSUI, H., KOISTINEN, M. 2008. The participatory research approach in non-Western countries: practical experiences from Central Asia and Zambia. Disability & Society, 23.

KHASNABIS, C., HEINICKE MOTSCH, K. 2008. The participatory development of international guidelines for CBR. *Leprosy Review*, 79.

KLERK, T. D. 2008. Funding for self-employment of people with disabilities. Grants, loans, revolving funds or linkage with microfinance programmes. *Leprosy Review,* 79.

KUMAR, R. 2011. *Research Methodology,* London, Sage Publications.

LANGEN, M. V. 2012. *The effects of Self-Help Groups on the experiences of stigma among people affected by leprosy in Western Nepal.* Master Thesis, VU University

LEPROSY REVIEW (http://www.leprahealthinaction.org/category/information/leprosy-review/) Accessed 7 May 2012

LINK, B. & PHELAN, J. C. 2006. Stigma and its public health implications. *Lancet,* 367.

MARTIKAINEN, P. 2002. Psychosocial determinants of health in social epidemiology. *International Journal of Epidemiology,* 31.

MARTINI, P. N., et al. 2012. A*nalisis keterlambatan penemuan penderita kusta di daerah endemis tinggi Prop. Jawa Tengah (Studi kasus di Kabupaten Blora dan Tegal).* Semarang: Universitas Diponegoro, Dinkes Prop. Jateng dan DKK Blora.

MAUTHNER, N. S., DOUCET, A. 2003. Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology,* 37.

MELIK, J. 2010. *Microcredit 'death trap' for Bangladesh's poor* (www.bbc.co.uk/news/world-South-Asia-11664632).

MENN, R. 1996. *Kleine historische Leprakunde. Die Klapper (*http://www.lepramuseum.de/96s05.htm) Assessed 6 Janurary 2012

MERCER, G., BARNES, C. 2002. Social Research and Disability (Unit 1). *Disability Studies - Module Four: Research Strategies & Design.* Leeds: University of Leeds.

MERCER, G. 2002. Re-viewing Disability Research. In: BARNES, C., OLIVER, M., BARTON, L. (ed.) *Disability Studies Today.* Cambridge: Polity Press

MERCER, G. 2004. From Critique to Practice: emancipatory disability research. In: BARNERS, C., MERCER, G. (ed.) *Implementing the Social Model of Disability: Theory and Research.* Leeds: The Disability Press.

MERSLAND, R. undated. *Microcredit for self-employed disabled persons in developing countries.* In: Social Science Research Network (http://ssrn.com/abstract=970519)

MILES, M. 1996. Community, Individual or Information Development? Dilemmas of concept and culture in South Asian disability planning. *Disability & Society,* 11**,** 485-500.

MILES, M. 2000. Disability on a Different Model: Glimpses of an Asian heritage. *Disability & Society,* 15.

MILLER, C., ALBERT, B. 2006. Mainstreaming Disability in Development Cooperation: Lessons from gender mainstreaming. In: ALBERT, B. (ed.) *In and out of the mainstream? Lessons from research on disability and development cooperation.* Leeds: The Disability Press.

NARAYA, D. 2002. *Empowerment and Poverty Reduction: A Sourcebook,* Washington, World Bank.

NAWIR 2009. *Expose Data Penyandang Cacat Berdasarkan Klasifikasi ICF Tahun 2009.* Jakarta: Sekretaris Jenderal Depsos RI

NLCP 2006. (National Leprosy Control Program) *Self-Care Groups in Indonesia. A manual for leprosy control programs*, Jakarta.

NLCP/NLR 2009. (National Leprosy Control Program / Netherlands Leprosy Relief) *Module Pelatihan Fasilitasi Kelompok Perwatan Diri,* Jakarta.

NLR 2009. (Netherlands Leprosy Relief) *National Meeting On Equal Access of People affected by Leprosy to General Hospitals*. Bogor.

NLR 2011. (Netherlands Leprosy Relief) *Country Policy for Indonesia 2011-2015*

OLIVER, M. 1986. Social Policy and Disability: some theoretical issues. *Disability, Handicap & Society,* 1.

OLIVER, M. 1992. Changing the Social Relations of Research Production? *Disability & Society*, 7.

OLIVER, M. 1996. *Understanding Disability - From Theory to Practice*, New York, Palgrave.

OLIVER, M. 2002a. *Using Emancipatory Methodologies in Disability Research - Emancipatory Research: A vehicle for social transformation or policy development*. 1st Annual disability Research Seminar. Dublin.

OLIVER, M. 2002b. Unit 4: Doing Disability Research (2): Emancipatory Research. In: SHELDON, A. (ed.) Dis*ability Studies, Module 3 - Culture, Researching Disability and Changing Practice*. Leeds: University of Leeds.

OLIVER, M. 2004. The Social Model of Disability in Action: If I had a Hammer. *In:* BARNES, C., MERCER, G. (ed.) *Implementing the Social Model of Disability: theory and research.* Leeds: The Disability Press.

ORR, N., PATIENT, D. 2005. Ethics of Empowerment (http://www.empow.co.za/docs/articles/ethics.html) Accessed 2007

PALYS, T. 2008. Purposive Sampling. In: GIVEN, L. M. (ed.) *The Sage Encyclopaedia of Qualitative Research Methods*. Sage: Thousand Oaks.

PARIDA, P., SINHA, A. 2010. *Performance and Sustainability of Self-Help Groups in India: A Gender Perspective.* Asian Development Review, Asian Development Bank*,* 27.

PARSONS, T. 1951. *The social system.* The Free Press, Glencoe, IL

PARSONS, K. 2011. *Paul Brand (*http://www.leprosymission.org.uk/about/about _the_leprosy_mission/brand.aspx) Assessed 3 June 2012

PerMaTa. 2012. (Perhimpunan Mandiri Kusta) http://permata.or.id/id/tentang-permata/organisasi-permata.html permata.or.id/. Accessed 23 May 2012

POESTGES, H. 2011. Leprosy, the key to another kingdom. *Leprosy Review,* 82.

PUPULIN, E. 2005. Disability and Rehabilitation: Reflections on working for the World Health Organisation. In: BARNES, C., MERCER, G. (ed.) *The Social Model of Disability: Europe and the majority world.* Leeds: The Disability Press.

QUINN, G., DEGENER, T. 2002. *The current use and future potential of United Nations human rights instruments in the context of disability.* New York and Geneva: UN.

RECKINGER, C. 2010a. Javanese Society and Disability. In: RECKINGER, C. & WINARNO, M. Y. (eds.) *Towards an Inclusive Society in Indonesia - A bridge over troubled water.* Yogyakarta: Caritas Germany.

RECKINGER, C. 2010b. An Introduction to Community Based Rehabilitation. In: RECKINGER, C. & WINARNO, M. Y. (eds.) *Towards an Inclusive Society in Indonesia - A bridge over troubled water.* Yogyakarta: Caritas Germany.

REEVE, D. 2004. Psycho-emotional Dimensions of Disability and the Social Model. In: BARNES, C., MERCER, G. (ed.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.

REIDPATH, D., et al. 2005. 'He hath the French pox': stigma, social value and social exclusion. *Sociology of Health & Illness,* 27.

RISDIANTOL, A. 2012. *Laporan Kegiatan Kunjungan ke Paguyuban (KPD) Tikung Lamongan Dan Paguyuban Sumberaji*, NLR

RYAN, S. 2010. 'Meltdowns', surveillance and managing emotions; going out with children with autism. *Health Place*, 16.

SCAMBLER, G., HOPKINS, A. 1986. Being epileptic: coming to terms with stigma. *Sociology of Health & Illness*, 8.

SCRI, 2010. (Strategic Country Review Indonesia) *NLR Strategic Country Review Indonesia, 2010.*, NLR

SENG, L. K. 2008. 'Our lives are bad but our luck is good': A Social History of Leprosy in Singapore. *Social History of Medicine,* 21.

SHAKESPEARE, T. 1996. Rules of Engagement: changing disability research. In: BARTON, L., OLIVER, M. (ed.) *Disability Studies: Past Present and Future*. Leeds: The Disability Press.

SHAKESPEARE, T., WATSON, N. 1997. Defending the Social Model *In:* BARTON, L., OLIVER, M. (ed.) *Disability Studies: Past Present and Future* Leeds: The Disability Press.

SHAKESPEARE, T., WATSON, N. 2001. Making the Difference - Disability, Politics, and Recognition. *In:* ALBERT, B. (ed.) *Handbook of Disability Studies.* London: Sage.

SHAKESPEARE, T. 2006. *Disability Rights And Wrongs*, New York, Routledge.

SHELDON, A. 2005. One World, One People, One Struggle? Towards the global

implementation of the social model of disability. In: BARNES, C., MERCER,

G. (ed.) *The Social Model of Disability: Europe and the Majority World*.

Leeds: The Disability Press.

SHELDON, A. 2010. Locating disability in the majority world: geography or poverty?

Disability and the majority world: challenging dominant epistemologies.

Manchester.

SIHOMBING, B. 2008. *Survey of Disability in People Affected by Leprosy in*

Indonesia. Jakarta: MOH Indonesia.

SIMANOWITZ, A. 2001. *Microfinance for the poorest- a review of issues and ideas*

for contribution of Imp-Act. Brighton: The Institute of Development Studies,

University of Sussex.

SINHA, F. 2006. *Self Help Groups in India - A study of the lights and shades*. India:

CRS, USAID, CARE, GTZ/NABARD.

SMALL, S. 1995. Action-Oriented Research: Models and Methods. *Journal of*

Marriage and Family, 57.

SMHF, 2012. (Sasakawa Memorial Health Foundation) (http://www.smhf.or.jp

/e/activities/hansen.html.) Accessed 22 May 2012

SMITH, R. A. 2007. Language of the Lost: An Explication of Stigma Communication.

Communication Theory, 17.

STAPLES, J. 2011a. Interrogating leprosy 'stigma': why qualitative insights are vital.

Leprosy Review, 82.

STAPLES, J. 2011b. Nuancing 'leprosy stigma' through ethnographic biography in South India. *Leprosy Review*, 82.

STEWART, R., BHAGWANJEE, A. 1999. Promoting group empowerment and self-reliance through participatory research: a case study of people with physical disability. *Rehabilitation in Practice,* 21.

STONE, E. 1996. A Law to Protect, a Law to Prevent: contextualising disability legislation in China. *Disability & Society,* 11**,** 469 - 483.

STONE, E. 1997. From the research notes of a foreign devil: Disability research in China. In: BARNES, C., MERCER, G. (ed.) *Doing Disability Research*. Leeds: The Disability Press.

SUNARMAN 2010. *Research Aksesibilitas Pasar* Solo, PPRBM Solo.

SUNARMAN 2011. *Laporan Perkembangan Program CBR Inclusive Leprosy, Phase II: Juni – Desember 2011*, di Kabupaten Tegal. Solo.

THOMAS, M. 2004. Challenges in leprosy rehabilitation. *Asia Pacific Disability Rehabilitation Journal,* 15.

THOMAS, M. 2008. Global trends in disability rehabilitation and their implications for leprosy programmes. *Leprosy Review,* 79.

TONELLI-NARDI, S. M., et al. 2011. Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Leprosy Review*, 82.

TSUTSUMI, A., et al. 2004. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. *Leprosy Review,* 75.

TSUTSUMI, A., et al. 2007. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. *Social Science & Medicine,* 64.

TUCKMAN, B. 1965. Development sequence in small groups. *Psychological Bulletin*, 63.

TUCKMAN, B., JENSEN, M. 1977. Stages of Small-Group Development Revisited. *Group & Organization Studies*, 2.

UN 2009. (United Nations) *Realizing the MDGs for persons with disabilities through the implementation of the World Programme of Action concerning Disabled Persons and the CRPD.*

UNDP 2011. (United Nations Development Programme) *Human Development Report 2011 - Sustainability and Equity: A Better Future for All*. New York

UPIAS 1976a (Union of the Physically Impaired Against Segregation) *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.

UPIAS 1976b. (Union of the Physically Impaired Against Segregation) Policy Statement.

VALENCIA, L. B. 1989. Social science research on social dimensions of leprosy: Where are we going from here? *International Journal of Leprosy,* 57.

VELEMA, J., ET A. 2008a. Evidence for the effectiveness of rehabilitation-in-the-community programmes. *Leprosy Review,* 79.

VELEMA, J. 2008b. Best practices in the socio-economic rehabilitation of persons affected by leprosy and other marginalised people in their communities: findings from nine evaluations in Bangladesh, Indian and Africa. *Asia Pacific Disability Rehabilitation Journal,* 19.

VERNON, A. 1999. The Dialectics of Multiple Identities and the Disabled People's Movement. *Disability & Society*, 14.

WALSHAM, G. 2006. Doing interpretive research. European *Journal of Information System*, 15.

WEHMEYER, M., BERSANI, H., GAGNE, R. 2000. Riding the Third Wave: Self-Determination and Self-Advocacy in the 21st Century. *Focus on Autism and Other Developmental Disabilities,* 15.

WEISS, M. G., RAMAKRISHNA, J. 2004. *Health-Related Stigma: Rethinking Concepts and Interventions*. Research Workshop on Health-Related Stigma and Discrimination. Amsterdam: Royal Tropical Institute.

WEISS, M. G. 2008. Stigma and the Social Burden of Neglected Tropical Diseases. *PLoS Neglected Tropical Diseases*, 2.

WELLER, D. J., MILLER, P. M. 1977. Emotional reactions of patients, family and staff in acute care period of spinal cord injury. *Social Work in Health Care*, 2.

WERNER, D. undated. *Strengthening the Role of Disabled People in Community Based Rehabilitation Programs*. (http://www.eenet.org.uk/parents/book/werner.doc)

WERNER, D. 1998. *Nothing about us, without us: Developing innovative technologies for, by and with disabled people*. Palo Alto, Health Wrights.

WHO 2002. (World Health Organisation) *Towards a Common Language for Functioning, Disability and Health - ICF,* Geneva.

WHO/ILEP 2007. (World Health Organisation / International Federation of Anti-Leprosy Associations) *Technical guide on community-based rehabilitation and leprosy,* Geneva / UK.

WHO 2009. (World Health Organisation) *Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy* (Plan Period: 2011-2015), New Delhi.

WHO 2010. (World Health Organisation) *Community Based Rehabilitation Guidelines,* Geneva.

WHO 2011. (World Health Organisation) *Guidelines for strengthening participation of persons affected by leprosy in leprosy services*, New Delhi.

WONG, M. L., SUBRAMANIAM, P. 2002. Socio-cultural issues in leprosy control and management. *Asia Pacific Disability Rehabilitation Journal,* 13.

WONG, M. L. 2004. Designing Programmes to Address Stigma in Leprosy: Issues and challenges. *Asia Pacific Disability Rehabilitation Journal,* 15.

YEO, R., MOORE, K. 2003. Including Disabled People in Poverty Reduction Work: "Nothing About Us, Without Us". *World Development,* 31.

YEO, R. 2005. Disability, poverty and the new development agenda. *Disability Knowledge and Research.*

YUNUS, M. 1998. Poverty alleviation: Is economics any help? Lessons from the Grameen bank experience. *Journal of International Affairs,* 52.

YUNUS, M. 2005. *Grameen Bank's Struggling (Beggar) Members Programme* (http://www.grameen.com/index.php?option=com_content&task=view&id=771&Itemid=740) Accessed 10 December 2011

ZUIDERHOEK, B. 1993. The approach to the leprosy problem in the past in Indonesia. *Tropical and Geographical Medicine,* 45.

Annex I: Research Locations

Location 1

Location: An urban leprosy settlement in the province of South Sulawesi.

Start: 2008. The SHG developed from a self-care group with the help

of an INGO.

Members: 25 members, 90% are female; all of them have been affected by

leprosy. The average age is around 45; members have basic

education or none at all, their income is derived from small trade,

day labour and begging. As common for people living in leprosy

settlements, their impairments are comparatively severe.

Main focus: Income generation activities, self-advocacy.

External influence: Many SHG members are, too, member of a DPO that developed

in the settlement parallel to the SHG, and are therefore involved

in advocacy and dissemination of information about leprosy with

the aim to reduce stigma. The SHG has been supported with

training, start-up funds and external facilitation by an INGO and

several local organisations, most have phased out by now. The

local government is supporting people in the settlement with food

rations.

Location 2

Location: A rural area in the province of East Java.

Start: 2010. The SHG developed from a self-care group with the help

of a DPO.

Members: 13 members, 80% are male; all of them have been affected by leprosy. Age ranges from 20 to 60 years; most members have basic education, their income is derived from small-scale farming. The economic status is generally low.

Main focus: Income generation activities, self-advocacy.

External influence: The DPO of people affected by leprosy regularly visits and provides guidance to this SHG. Support in form of training and start-up funds has been given by an INGO. Local health services gave technical support when the SHG was still a self-care group.

Location 3

Location: A semi-urban and rural area in the province of Central Java.

Start: 2011. The SHG was formed as a pilot project to bring together people affected by leprosy and other disabled persons in one SHG.

Members: The main group has 100 members including 25 people affected by leprosy. The group is split into four regional groups that meet separately. 60% are male; the average age is around 35 years. Most members have basic education and earn their living with small trade and farming.

Main focus: Income generation activities, advocacy and the development of a local support system to enhance access to services and inclusion into community activities.

External influence: Four local CBR workers, two of them are disabled, guide the four regional groups. A CBR team, led by a disabled activist,

supervises the pilot project and visits regularly. The project is supported by an INGO, and, slowly beginning, by the local government.

Location 4

Location: A rural area in the province of East Java.

Start: 2011. The SHG was started by one of its members after he joint an awareness workshop by the DPO of people affected by leprosy.

Members: 20 members, 65% are male; all of them have been affected by leprosy. The average age is around 40 years; most members have basic education, their income is derived from farming.

Main focus: Self-care, savings, advocacy, no income generating activities yet.

External influence: The group is regarded as a local branch of the DPO, but no regular visits or guidance by the DPO headquarters is available so far. On invitation of the local health services the group conducts meetings in their communal health centre.

Annex II: Criteria for Purposive Sampling of Participants for Semi-structured Interviews

- Representing 'typical' SHG members, not unusual or extreme in their socio-economic status or attitude

- Communicative and willing to share information

- Actively attending SHG meetings

- Time available

- Able to speak Indonesian, Makassar, Bugis or Javanese

- Not often interviewed before (to avoid repetition of standard replies)

- Gender of participants should reflect the gender composition in each group

Annex III: Overview of Participants

All names are pseudonyms.

Location 1

Participants of semi-structured interviews:
1. Bapak Serang
2. Ibu Utari
3. Ibu Sita

Participants of FGD: 23 group members

Location 2

Participants of semi-structured interviews:
4. Ibu Indah
5. Bapak Kus
6. Bapak Bambang

Participants of FGD: 8 group members

Location 3

Participants of semi-structured interviews:
7. Bapak Slamet
8. Bapak Wahyu
9. Ibu Wulan
10. Bapak Tri
11. Bapak Purnama

Location 4

Participants of semi-structured interviews:
12. Bapak Eko
13. Bapak Iman
14. Bapak Arif
15. Ibu Mawar

Participants of FGD: 19 group members

Annex IV: Interviewing Guide

(Translation)

1. Introducing myself and getting to know the participant:

Semi-structured interview: Name, work, daily activities, family, etc.

Focus Group Discussions: How long did group exists, how many members, structure, etc.

2. Do you (or do you not) face any problems / difficulties in daily life, regarding, for example:

Semi-structured interview:
- Health (e.g., daily activities, access to services)
- Relationship with community, religious activities
- Work, income
- Family
- Feelings, other problems relating to the former infection with leprosy

Focus Group Discussions: Not asked but noted when they speak about it

3. Membership in the SHG (*for both interviews and FGD*)

    I. General opinion

    II. In the beginning
- How did you come to join the SHG
- What was your expectation of being a member in the SHG

    III. Opinion about activities in the SHG, e.g.:
- Saving and loans
- Advocacy
- Self-care
- Others, like vocational training, etc.

    IV. Membership
- Do you prefer to do these activities alone or in the group (e.g., loans)
- Opinion about a SHG with only people affected by leprosy
- Opinion about a SHG together with other disabled people

    V. Hopes for the future
- Expectations and hopes
- What can you or others do to achieve these?

4. Relationship with and support by local government (*for both interviews and FGD*)

Annex V: Informed Consent Form

(Translation)

Informed Consent for Interviews and FGDs

Before the interview / FGD, the interviewer explains to the participant :

- **Introduction**: Your name and position, the organisation responsible for this study (NLR)
- **Aim**: You are member of a team that tries to understand how the participant sees his / her membership in the SHG. You like to know his / her opinion and experiences as SHG member and how far this has helped to overcome daily difficulties.

  Ask the participant whether he / she agrees to be asked about life, family, community and SHG. This information will be used to help supporting and improving SHGs in Indonesia for people affected by leprosy.

- **Explain about the interview:** The interview will take about 1-1.5 hours. It can be conducted in any place comfortable for the participant.

  Explain about the FGD: The discussion will take about 1.5 hours and can be conducted in any place comfortable for the participants.

- **Explain that you will revisit** the participant after a while to confirm whether your notes of his / her information were correct.

- **Explain the rights** of the participant**:** He / she is free to refuse to answer on any part of the interview or the FGD, or to refuse to answer at all. He / she can stop the interview or his / her participation in the FGD at any time.

  There will be no immediate benefit for the participant, but we will be happy to thank the participant with a small gift (2 kg sugar)

- **Confidentiality**: The identity of the participant will be kept confidential. His / her name will not be given to any other party.

- **Ask the participant**: Does he / she have any other question regarding this study?

  Offer to contact you if there are any other questions at a later point. Note your cell phone number for him / her.

- **Consent: Ask** the participant whether he / she agrees to this interview / FGD:

Consent of the Participant:

I have read or have heard the information above. I received answers on all questions I had regarding this study. I herewith agree to participate in this study.

Participant Number: _____

Signature participant: _____ Date: _____

Signature interviewer: _____ Date: _____

If the participant cannot write, ask him for his finger print.