

**Disability Organisations as Empowering Settings:  
The case of a local disability organisation  
in Yogyakarta Province, Indonesia**

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## Abstract

The importance of empowering settings as a vehicle for social change has been documented in the community psychology literature. However, more research is needed to understand the processes and mechanisms through which participation in a particular setting may function as an empowering pathway for marginalised individuals. This research investigated how *Forum Peduli Difabel Bantul* (FPDB), a local disability organisation in Yogyakarta Province, Indonesia, has functioned as an empowering setting for its members. Informed by the transformative paradigm in disability research and constructivist grounded theory, the study examined the socio-psychological processes and mechanisms through which this organisation has enabled its members to resist the pervasive discrimination and marginalisation commonly imposed upon people with disability in the Indonesian society. The research data were collected from various sources including interviews with 18 members of FPDB, and were analysed using a grounded theory approach.

The findings of this current study suggest that FPDB has been experienced as an empowering setting by functioning both as a transformative incubator and a mindset changer. Through these two enabling functions, FPDB has been able to generate three types of meaningful resources including relational, instrumental and symbolic. By having access to these resources, the participants have been enabled to tackle the psychological, political and cultural dimensions of their discrimination and marginalisation.

Overall, the findings of this current study are consistent with previous research investigating the nature and characteristics of empowering settings. However, this study has also generated some insights that reflect the particular context in which the setting is situated. Ways in which such insights may extend the theoretical understandings of empowering settings in the field of community psychology are discussed.

## Declaration

I, Monica Eviandaru Madyaningrum, declare that the PhD thesis entitled *Disability Organisations as Empowering Settings: The case of a local disability organisation in Yogyakarta Province, Indonesia* is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signature

A solid black rectangular box used to redact the signature of the author.

Date 12/07/2017

## **Dedication**

To the individuals and organisations in Indonesia that have tirelessly worked for a more just and inclusive society, which respects the rights of *difabel* people.



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# **Chapter 1**

## **Introduction**

### **1.1. Study Rationale**

Community psychology is a field of study guided by a set of values and principles, which are aimed at promoting people's wellbeing, especially those who are marginalised in society (Bond, Serrano-García & Keys, 2017; Rappaport & Seidman, 2000). Such an orientation has encouraged scholars and practitioners in this field to work with disadvantaged individuals and groups, including people with disabilities (PWD).

Global reports on disability (e.g., WHO, 2011) indicate that PWD in many parts of the world continue to experience systemic injustice and inequality that have placed them among the most disfranchised groups in society. According to the World Health Organisation (WHO), approximately 15% of the world's population or about 1.1 billion people live with disability. Eighty percent of these live in developing countries like Indonesia (Richardson, 2017).

Disability problems in developing countries are generally complicated by a range of socio-economic and political factors, such as poor resources and lack of government political commitment to fulfil the rights of PWD (Shakespeare, 2012). In Indonesia, for instance, PWD remain prominently marginalised in various aspects of their life due to the existing discriminatory socio-economic and political systems (Adioetomo, Mont & Irwanto, 2014). As a result, the living conditions of many PWD in this country are generally characterised by multi-dimensional disadvantages, including having low economic status, poor health conditions, lack of education and being socially excluded (Adioetomo et al., 2014; Irwanto, Kasim, Fransiska, Lusli & Siradj, 2011; Kusumastuti, Pradnasari & Ratnawati, 2014).

Ten percent of the Indonesian population, or about 24 million people, live with disabilities (Adioetomo et al., 2014). However, their lived experiences and struggle are still largely unrecognised and poorly understood. The scarcity of disability studies is one of the situations that illustrate the lack of attention commonly experienced by PWD in Indonesia (Yulianto, 2011).

The lack of adequate knowledge on disability issues is also a concern shared in the field of community psychology. The collective struggles of PWD are generally centred on issues such as social justice, diversity and self-determination (Watson, Roulstone & Gibbons, 2012). These issues are also central to community psychology. Despite sharing similar concerns, community psychology still generates limited understandings of the lived experience of PWD (Balcazar & Suarez-Balcazar, 2017; Goodley & Lawthom, 2005, 2006; McDonald, Raymarker & Gibbons, 2017; White, 2010). For instance, McDonald et al. (2017) argue that:

... [R]elatively few community psychologists meaningfully include people with disabilities in their work. Perhaps in part a reflection of this exclusion, community psychology has yet to develop a collective consciousness of how to leverage community psychology theory, research and action to improve the lives of people with disabilities (p. 403).

The history of disability studies suggests the crucial contributions of empirical research in advancing people's understandings and responses to disability (Goodley, 2011; Shakespeare, 2015; Watson et al., 2012). Progressive disability studies are considered as a key to better disability politics (Shakespeare, 2015). The development of critical disability theories, such as the social model of disability (Oliver, 2009; Shakespeare, 2006), has demonstrated how scholarly works can significantly influence the course of disability policies and activism. In Britain, for instance, the rise of the social model of disability drove the emergence of politically oriented disability organisations in the 1980s that challenged the dominant charity-based approaches to disability (Oliver, 2009).

Despite its potential, research on disability issues may become another mechanism whereby the subordination of PWD are reproduced and reinforced (Goodley, 2011; Moore, Beazley & Maelzer, 1998; Shakespeare, 2015). The history of disability studies has shown that even well intended research may end up as a form of patronising practice by perpetuating the stigmatising views of PWD as inherently problematic and inferior individuals (Goodley, 2011; Moore et al., 1998). Countering such a practice, scholars in critical disability studies have promoted models of research that may contribute to challenging the oppression of PWD (e.g., Goodley, 2011; Moore et al., 1998; Tregaskis & Goodley, 2005). These models of research include studies that seek to understand how disability, as a form of social oppression, can be resisted and transformed (e.g., Abberley, 1987; Charlton, 2006; Mackelprang & Salsgiver, 2015).

In their attempts to contribute to dismantling the oppression of PWD, some scholars have investigated how disability organisations may function as an advocacy group (e.g., Blackmore & Hodgkins, 2012, Campbell & Oliver, 1996; Dowse, 2001). These studies have examined the potential of disability organisations as a political platform for PWD to consolidate their collective struggle against discriminatory systems and practices. In the Indonesian context, this kind of study is exemplified by Yulianto's (2011) research, which looks at the role of local disability organisations in developing the disability movement in the country. His study is one among only few studies into disability organisations in Indonesia.

The work of some of the scholars above has been focused on analysing the role and significance of disability organisations as forms of political activism. These studies have demonstrated the contribution of disability organisations in promoting structural and cultural changes that are instrumental for advocating the rights of PWD. However, there have only been limited studies that bring socio-psychological perspectives to investigate people's experiences in disability organisations. There remains a gap in understanding how

participation in such organisations may enable people to experience personal and collective empowerment (Balcazar & Suarez-Balcazar, 2017; McDonald et al., 2017). This gap implies the need for studies, which aim to explicate the socio-psychological processes and mechanisms through which disability organisations can function as enabling sites for its members.

Informed by this gap, I conducted this current study, which investigated how a local disability organisation in the Bantul District of Yogyakarta Province, Indonesia, has functioned as a transformative social setting for its members. By undertaking this study, I wanted to contribute to expanding community psychology's discussions on the role of such settings as a catalyst of social change.

Understanding how social settings can promote people's wellbeing is an area of inquiry that is central to community psychology (Aber, Maton & Seidman, 2011; Rappaport, 1995; Sarason, 1972; Seidman & Capella, 2017). Such an inquiry reflects the identity of community psychology as a field of study, which aims to understand individual behaviours in social contexts (Trickett, 1996, 2009). Particularly with regard to its ethical commitment to work with marginalised individuals and groups, community psychology has been interested in investigating how social contexts can promote people's liberation, both at the personal and communal levels (Aber et al., 2011; Rappaport, 1987, 1995). Such investigations are crucial in advancing the orientation of community psychology toward preventive and strength-based approaches to research and action (Aber et al., 2011).

The idea of empowering settings is one of the theoretical constructs in community psychology that aim to explicate how social contexts can act as enabling environments (Aber et al., 2011; Maton, 2008; Seidman & Capella, 2017). This concept has generated studies that investigate the characteristics of social spaces, which can facilitate personal development, community betterment and positive social changes (e.g., Fedi, Mannarini & Maton, 2009;

Maton, 2008; Maton & Brodsky, 2011; Peterson & Speer, 2000). Combining two key metaphors in community psychology (i.e., empowerment and settings), this concept has the potential to uncover how participation in a particular group or organisation may enable marginalised individuals to generate resources, forge solidarity and tackle their disadvantages (Aber et al., 2011).

Studies on empowering settings have generated a range of general features that characterise enabling social environments. Characteristics such as promoting personal growth, fostering supportive interpersonal relations and encouraging collective actions are some of the features identified in various types of enabling social contexts (Maton & Brodsky, 2011; Maton & Salem, 1995; Peterson & Speer, 2000). However, in line with the ecological thinking in community psychology, studies on empowering settings suggest that each context has specific factors and mechanisms that shape its function as an enabling environment (Maton & Salem, 1995; Rappaport, 1987; Trickett, 2011). How a particular setting acts as a transformative site for its members reflects the dynamic interactions between the internal factors and the broader socio-historical and cultural context in which the setting is situated.

This understanding underlines the importance of developing studies that investigate characteristics, which are unique to a particular group or organisation, in order to generate contextual knowledge on empowering settings (Maton & Salem, 1995). Encouraged by such an understanding, therefore, I have aimed to identify socio-cultural factors that allow the disability organisation being studied to function as an empowering setting. Developing contextual knowledge on the role and potential of disability organisations as an empowering setting is crucial given the nature of disability as a socio-historically and culturally situated phenomenon (Goodley, 2011). As argued by McDonald et al. (2017), studies on disability need to consider, “interactions among individuals with disabilities and social, built, and

political environments, and emphasize the significant role of contextual factors in creating disability and its impacts” (p. 404).

This need for studies that promote ecologically diverse understandings of disability is also instrumental in addressing the scarcity of disability research, which is conducted in areas outside of North American and Western European countries (Goodley, 2013). Based on such a trend, Goodley argues that disability studies may risk becoming a colonising practice through the domination of Global North perspectives on disability and the imposition of universal assumptions.

Informed by the concerns and research gap presented in this section, this thesis was set out to answer the following two questions:

1. How does a local disability organisation in Bantul District, Yogyakarta Province, Indonesia function as an empowering setting for its members?
2. What are the socio-psychological processes and mechanisms that enable this organisation to function as an empowering setting?

## **1.2. Disability Terminology**

Terminologies used to identify and label disabilities play a crucial role in disability studies. In this section, I explain the rationale that underpins the choice of disability terminologies utilised in this study. As argued by some scholars, disability terminologies may contribute to reproducing or contesting disability as a form of social oppression (e.g., Mackelprang & Salsgiver, 2015; Marks, 2014). For instance, the emergence of the term PWD reflects the history of resistance against the use of derogatory labels to identify disability, such as handicap or abnormal (Mackelprang & Salsgiver, 2015). The term PWD challenges deficit-oriented labelling of disability by emphasising the use of person-first language. Such an emphasis rejects types of labelling that place people’s disability as the defining feature of

their entire identity or personhood (Dunn & Andrews, 2015; Mackelprang, 2010; Mackelprang & Salsgiver, 2015). “Person-first language acknowledges the basic humanity of individuals with disabilities irrespective of their individual trait and characteristics” (Mackelprang & Salsgiver, 2015, p. 25).

Nowadays, the use of person-first language has become more common. For instance, the 6<sup>th</sup> edition of the American Psychological Association (APA) Publication Manual explicitly recommends person-first language to describe groups of people with disabilities (American Psychological Association, 2010). However, the use of person-first language has created its own contestation. For example, in the United Kingdom the use of disability-first language (i.e., disabled people) is preferred to emphasise the understanding of disability as a socially constructed phenomenon. This preference is underpinned by an assumption that person-first language implies the understanding of disability as a problem that is located within the persons (Mackelprang, 2010; Mackelprang & Salsgiver, 2015). As argued by Mackelprang and Salsgiver (2015), “Blacks and whites do not want to be called persons with blackness or persons with whiteness ... Similarly, disability-first language (e.g., disabled man, disabled woman, and disabled person) embraces disability as a characteristic and identity” (p. 27).

This different point of view reflects the importance of being mindful in selecting terms to describe disability, considering that each term ascribes its own particular meanings, assumptions and connotations. Moreover, this debate underlines the importance of respecting people’s rights and determination to be called by whatever names they prefer (Mackelprang & Salsgiver, 2015). In line with such an argument, therefore, I intentionally did not translate into English the term ‘*difabel*’ that was used by the participants to describe themselves. This word appears in a number of direct quotations from the interviews with the participants that are presented in the findings chapters (chapter 7 and 8).

*Difabel* is the preferred term to describe disability in the Indonesian context. This term is the Indonesian version of “differently abled people” (Suharto, Kuipers & Dorsett, 2016, p. 700). Advocated by disability activists and scholars since the mid of 1990s, this term is intended to resist the use of deficit-oriented labelling of disability which is still common in Indonesia. Suharto et al. (2016) argue that the term *difabel* “provides a more positive characterisation of people with impairments and reminds English speakers of the importance of acknowledging abilities and respecting differences (p. 706). In the Indonesian context, the attempt to mainstream the term *difabel* has become one of the key agendas advocated by disability activists and organisations. For me, such a context highlights the importance of respecting the participants’ choice to use the term *difabel* in describing themselves.

In addition to the use of the term *difabel*, in this thesis I also use both the person-first (PWD) and disability-first language (disabled people). I use the term PWD when I express my own arguments or analysis considering that the APA Publication Manual, which is applied in this thesis, endorses the use of this term. The term disabled people is mainly used when I cite other scholars’ work where they used this term in their original articles.

### **1.3. Structure of the Thesis**

Guided by the research questions, I was oriented toward theoretical and methodological frameworks that may generate contextual knowledge on disability as well as the role of social settings as sites of empowerment. These frameworks and the findings of this current study are presented in the following nine chapters:

**Chapter two** presents conceptual frameworks adopted in this current study. This chapter consists of two major reviews. The first part discusses a number of concepts related to how disability is approached in this current study. These include the concept of disability as social oppression (Abberley, 1987; Barnes & Mercer, 2003; Charlton, 2006; Mackelprang &



Salsgiver, 2015), the social model of disability (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Thomas 2002) and ableism (Goodley, 2014; Mackelprang & Salsgiver, 2015). Drawing on these concepts, I focus on examining the nature of disability as a socio-politically situated phenomenon and its implications for understanding the discrimination and marginalisation of PWD. The second part of chapter two examines the concept of empowering settings (Aber et al., 2011; Maton, 2008; Rappaport, 1995) and its relevant for investigating people's participation in disability organisations. I start this part by reviewing some major theories that reflect the importance of social settings as foci of research in community psychology. Then, I examined three conceptual approaches that may explain the nature of empowering settings. These approaches are community narrative (Mankowski & Rappaport, 1995, 2000; Rappaport, 1995, 2000), social representations (Flick, 1995; Howarth, 2001, 2006) and counterspaces (Case & Hunter, 2012).

**Chapter three** situates the socio-historical context of the present study. In this chapter I review relevant literature and reports that describe how disability has been generally approached in Indonesia and how this impacts on the construction of PWD as a marginalised group in the society. I also included an overview on the emergence of the disability movement in Indonesia and how it has influenced the development of local disability organisations. In addition, I examine a number of studies on Javanese culture to explain the cultural context in which the disability organisation being studied is situated.

**Chapter four** describes *Forum Peduli Difabel Bantul* (FPDB), a local disability organisation in the Bantul District of Yogyakarta Province, Indonesia, which is the site of this current study. This chapter begins with a description of the socio-historical background that drove the development of this organisation. I particularly focus on explaining the socio-political context of Bantul as a district severely affected by a natural disaster in 2006 and its

influence on the emergence of FPDB. This chapter also details the current profile of this organisation, including its members and core activities.

**Chapter five** provides an overview of the methodological framework applied in the present study. In this chapter, I discuss the rationale for adopting the transformative paradigm in disability research as proposed by Mertens, Sullivan and Stace (2011), as well as the choice to employ constructivist grounded theory as the methodological framework (Charmaz, 2000, 2007, 2009). I also argue how constructivist grounded theory may complement the implementation of the transformative paradigm in disability research by outlining a set of data collection and analysis method which are consistent with the ethical positioning advocated by this paradigm. The process of data collection and analysis itself is detailed in **Chapter six**. In this chapter, I also describe the profile of the participants and the fieldwork process.

**Chapter seven** and **eight** present the overall findings of this current study as represented in two conceptual categories, namely *FPDB as a Transformative Incubator* and *FPDB as a Mindset Changer*. The first conceptual category is particularly concerned with the social processes and practices that have characterised FPDB as an empowering setting, while the second conceptual category discusses the empowering outcomes experienced by the participants.

Following the presentation of the findings, **chapter nine** presents an overall discussion that addresses the research questions. In this chapter, I discuss how FPDB has functioned as an empowering setting by generating three types of meaningful resources (i.e., relational, instrumental and symbolic). I then discuss how these resources have created pathways for the participants to tackle the psychological, political and cultural dimensions of their discrimination and marginalisation.

**Chapter ten** closes this thesis by outlining a number of theoretical, methodological and practical implications for this study. The study limitations, and recommendations for future research are also discussed.

## **Chapter 2**

### **Disability Organisations as Empowering Settings**

In this chapter, I review literature on disability and the concept of empowering settings, which have become the theoretical context of this research. I start this chapter by reviewing literature that discusses disability as a form of social oppression (e.g., Abberley, 1987; Barnes & Mercer, 2003; Mackleprang & Salsgiver, 2015). Drawing on this literature, I focus on examining disability as a socio-political construct and the implications this has had for understanding the multi-dimensional disadvantages commonly experienced by PWD. Furthermore, I also discuss how the understanding of disability as social oppression has driven the development of disability organisations that function as sites of resistance for PWD.

Following the discussion on disability, I examine the concept of empowering settings as a theoretical framework that may explicate how participation in disability organisations is experienced as a transformative process (e.g., Aber et al., 2010; Maton & Salem, 1995; Seidman & Capella, 2017). First, I discuss a number of defining characteristics of empowering settings. Then, I outline three theoretical approaches that may explain the mechanisms and pathways through which the concept of empowering settings links participation and empowerment. The three theoretical approaches are community narrative (Mankowski & Rappaport, 1995, 2000; Rappaport, 1995, 2000, 2011), social representations (Flick, 1995; Howarth, 2001, 2006) and counterspaces (Case & Hunter, 2012). Lastly, I develop a discussion that explores the understanding of disability organisations as empowering settings.

## **2.1. Disability as Social Oppression: Meanings and Implications**

Literature on disability has documented the long history of discrimination and marginalisation, which has placed PWD among the most “disenfranchised and unempowered groups in the community” (White, 2010, p. 438). Current global reports on disability (e.g., WHO, 2011) have also indicated that pervasive discrimination and marginalisation still continue to be a common experience for PWD in many parts of the world. Against such disadvantages, disability scholars have developed theoretical frameworks, which are targeted to amplify the struggle of PWD for social justice and equality (e.g., Abberley, 1987; Goodley, 2011, 2014; Mallett & Runswick-Cole, 2014; Oliver, 2009; Roulstone, Thomas and Watson, 2012; Shildrick, 2012). The theorisation of disability as social oppression is one such framework.

Disability as social oppression represents a paradigmatic shift in the way disability is understood by viewing it as primarily a product of disabling social and physical environments, rather than as a result of the physical impairment itself (Abberley, 1987; Barnes & Mercer, 2003; Charlton, 2006; Mackelprang & Salsgiver, 2015; Oliver, 2009). Advocated by disability activists and academics since the 1970s, the understanding of disability as social oppression emerged from awareness that physical impairment is not only a biological, but also “a socio-political, cultural and relational phenomenon” (Goodley, 2011, p. 49). How people experience, give meaning and respond to physical impairment is largely determined by the interplay of socio-political and cultural forces, which govern people’s social functioning and relations. In this sense, multi-dimensional disadvantages commonly experienced by PWD are primarily a product of socio-political and cultural systems, which have placed PWD as a subordinate group (Barnes & Mercer, 2003; Charlton, 2006; Goodley, 2011; Mackelprang & Salsgiver, 2015; Oliver, 2009).

It is this awareness of disability as socio-political and historical product that has eventually led to the understanding of disability as social oppression. This understanding views disability as a problematic situation predominantly caused by oppressive social structures, which have placed PWD in an inferior position to other members of society because of their physical impairment (Abberley, 1987). By locating the problems within the social structure of a society, the understanding of disability as social oppression has transformed public discourses on disability in at least two significant ways.

Firstly, the understanding of disability as social oppression has led to the modification of how impairment and disability is defined (Charlton, 2006; Goodley, 2011; Oliver 2009). Previously, there was a tendency to mainly associate disability with individuals' inability to perform an activity due to their impairment (e.g., WHO, 1981). In this sense, disability tended to be seen as a form of personal deficiency that limited the persons' capacity to function in manners, which were considered to be the 'normal standard' of human capability. Rejecting such a view, the understanding of disability as social oppression has generated definitions that emphasise the socio-political aspects of disability (Abberley, 1987; Barnes & Mercer, 2003; Charlton, 2006; Mackleprang & Salsgiver, 2015).

The definition proposed by the Disabled People's International (DPI), in the early 1980s was an example that reflected the shift toward a socio-politically oriented understanding of disability. As cited in Goodley (2011), DPI defined impairment and disability as:

Impairment – is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability – is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (p. 8).

This definition from DPI illustrates how disability is understood as a social disadvantage that is caused by the presence of structural barriers, which exclude PWD from their community.

Secondly, the understanding of disability as social oppression has contested the medical and individual perspectives on disability, which previously had become the dominant paradigm (Barnes & Mercer, 2003; Barnes, Oliver & Barton, 2002; Oliver, 2009; Thomas, 2002). Rooted on the biological assumptions of normality, medical and individual perspectives tend to view disability as a form of physical abnormalities or dysfunctions that requires individual-based curative or corrective interventions (Barnes & Mercer, 2003; Goodley & Lawthom, 2006; Mackelprang & Salsgiver, 2015). Such a view has therefore generated the dominant portrayal of disability as a personal inferiority, which may evoke negative psychological responses such as grief, pity, shame, fear and disdain. Overall, medical and individual perspectives have shaped the construction of disability primarily as a personal tragedy rather than as a form of social injustice (Barnes & Mercer, 2003; Goodley & Lawthom, 2006; Mackelprang & Salsgiver, 2015).

Contesting these medical and individual perspectives, the understanding of disability as social oppression advocates a view that disability is mostly a social problem rather than a form of deviation or personal weakness (Abberley, 1987; Barnes & Mercer, 2003; Charlton, 2006; Mackelprang & Salsgiver, 2015). This understanding assumes that the problems with disability do not primarily require the rehabilitation of PWD, rather the historical, cultural, political and economic systems which have produced, as well as sustained, unequal relations between PWD and non-disabled people (Abberley, 1987). In this sense, the understanding of disability as social oppression has defied the view of PWD as victims of their own personal deficiency. Instead, this understanding has raised awareness that PWD are underprivileged members of a society whose human rights have been systematically violated (Abberley, 1987; Barnes & Mercer, 2003; Charlton, 2006; Mackelprang & Salsgiver, 2015). As a result, the living conditions of PWD are generally marked with “material disadvantages, powerlessness and demeaning cultural stereotyping” (Barnes & Mercer, 2003, p. 41). Such difficulties have

often been exacerbated by the economic demands of an industrial society that have created the stigmatisation of PWD as unproductive society members (Oliver, 2009).

The theory of disability as social oppression has generated profound conceptual implications. Abberley (1987) outlined five ways through which this theory may enable researchers to attend to the complexity of disability as a socioeconomic phenomenon. These are: (a) emphasising the social origins of impairment, (b) recognising the multi-dimensional disadvantages inflicted on PWD, (c) understanding disability as an historical product, (d) valuing the lived experiences of PWD, and (e) advocating the transformation of the lives of PWD (Abberley, 1987).

## **2.2. The Social Model of Disability**

In the field of disability studies, the understanding of disability as social oppression has been strongly linked to the development of the social model of disability (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas, 2002). Originally developed in the context of the disability movement in Britain, this model views that disability is a product of how a society responds to people with impairment, rather than the impairment itself (Oliver, 2009, p. 43). Mike Oliver, the proponent of this theory, argues that the social model of disability is “... a way of applying the idea that it was society and not people with impairments that should be the target for professional and intervention practice” (Oliver, 2009, p. 43).

By enabling PWD to view their disadvantages as a socially constructed situation, the social model of disability has driven the development of a politically oriented disability movement in Britain (Oliver, 2009; Oliver & Zarb, 1989). Instead of focusing on medical and welfare interventions, disability activists and scholars have advocated social changes which are aimed at removing disabling barriers that have produced and sustained the myriad of



disadvantages experienced by PWD (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas, 2002). Such a movement has eventually become a point of reference for similar disability activisms in other countries, including Indonesia (Yulianto, 2011).

By framing disability as primarily a political issue, the social model reflected a paradigmatic shift from the medical and individual model, which had previously been the dominant framework in defining and approaching disability (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas, 2002). Through the lens of the individual model, disability is generally viewed as a personal problem that requires medical interventions to help PWD adapt to a disabling society. Opposing such a view, the social model advocates the understanding of disability as a form of social injustice that demands social action targeted to eliminate disabling barriers in a society (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas, 2002). Furthermore, the social model also puts forward the human rights-based approach to disability to challenge the patronising approaches that generally characterise the medical model. The human rights-based approach reaffirms the understanding that disability is a problem that is determined by the extent to which a society meets its political responsibility to fulfil the rights of PWD (Oliver, 2009).

Emphasising political interventions does not mean that the social model rejects the relevance of medical treatments to disability (Oliver, 2009). Rather, the social model of disability emphasises the importance of acknowledging and respecting the rights and autonomy of PWD to determine the types of interventions they need. In this sense, adopting the social model of disability requires conscious efforts to prevent and disrupt modes of interventions that may perpetuate the dominant portrayal of PWD as inferior individuals (Barnes, 2012; Oliver, 2009; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas,

2002). As a result, the social model of disability has also draw attention to the importance of recognising and unpacking the socio-political and cultural mechanisms through which the marginalisation of PWD has been produced and perpetuated (Oliver, 2009).

Informed by the social model of disability, I opt for conceptual frameworks that allow me to understand the way disability as social oppression has operated in the particular society where I undertake my study. One of such conceptual frameworks is the notion of ableism, which is detailed in the next section.

### **2.3. Ableism and Psychology**

Mackelprang and Salsgiver (2015) define ableism as:

[T]he belief that because persons with disabilities are not typical of the nondisabled majority, they are inferior. Ableism precipitates devaluation, while the results of devaluation, including exclusion and ostracism, reinforce the attitudes, actions and policies of those who oppress (p. 105)

By defining ableism as a belief, Mackelprang and Salsgiver (2015) point to how oppression towards PWD may be deeply rooted in people's cognitive and emotional systems. In this sense, countering oppression towards PWD entails a process of deconstructing ableism as a personal and collective belief system that underpins non-factual negative judgements commonly attributed to PWD (White, 2010).

Ableism is a problematic belief system for both non-disabled people and PWD. For non-disabled people, ableism can shape their prejudicial attitudes toward PWD, such as associating disability with pity and weaknesses. Such attitudes may then reinforce the 'victim-blaming' perspective, in which disability is primarily viewed as a problem of a person with impairment (Goodley, 2014; Mackelprang & Salsgiver, 2015). Prejudicial attitudes toward PWD are usually reproduced and sustained through therapeutic and intervention programs that are targeted to rehabilitate PWD so that they can fit into the ableism-driven society. The perpetuation of ableism often creates social pressures for PWD to internalise disempowering

mindsets and attitudes. These include viewing themselves as deficient individuals, which may contribute in sustaining their own marginalisation (Mackelprang & Salsgiver, 2015).

Understanding the notion of ableism is instrumental in unpacking the psycho-emotional dimensions of disability. According to Reeve (2006), understanding the more “personal experiences” of oppression, which operates at emotional levels, is as crucial as addressing the “public experiences” of oppression, such as the issue of inaccessible environments (p. 95). Reeve’s argument is a reminder that disability as social oppression may not be merely manifested through intentional and direct injustice. Rather, oppressive treatments toward PWD can also arise through unintended and subtle acts such as “being stared at or patronised by strangers” (Reeve, 2006, p. 95).

Ableism is a useful concept to unpack the socio-psychological mechanisms that have produced and sustained the oppression of PWD (Goodley & Lawthom, 2006; Reeve, 2012). Unpacking such mechanisms is particularly important in the field of psychology. Influenced by biomedical approaches to the mind and body, there was a time when psychological approaches to disability were predominantly infused by the understanding of disability as a form of individual abnormalities (Goodley, 2011, 2012; Goodley & Lawthom, 2006). Such approaches were generally underpinned by psychology’s emphasis on the concept of normal development, which suggest that there exist standard criteria of individuals’ physical and psychological functioning (Goodley, 2011). As a result, psychology both as a field of study and practice might have contributed in reproducing and reinforcing ableism through “normalising practices” that focus on making individuals adjust to their own impairment (Goodley & Lawthom, 2006, p. 5). Through such practices, the socio-political nature of disability was distorted and the difficulties experienced by PWD were mainly framed as a consequence of their physical impairment. Goodley (2011) underlines this point by arguing, “A key site of the oppression of disabled people pertains to those moments when they are

judged to fail to match up to the ideal individual; when they are categorised as embodying the failing individual” (p. 78)

The criticism on the role of psychology in reproducing and reinforcing ableism has driven the emergence of psychological studies, which are oriented toward critical approaches to disability (e.g., Goodley, 2011; Goodley & Lawthom, 2006; Olkin & Pledger, 2003). In the field of community psychology, the orientation toward critical approaches to disability has generated studies, which aim at amplifying the struggle of PWD for equality and social justice (e.g., Balcazar et al., 2012; Dowrick & Keys, 2001; McDonald, Keys & Balcazar, 2007; Radermacher, Sonn, Keys & Duckett, 2010). These studies seek to unpack the social mechanisms that have maintained the oppression of PWD, as well as explore strategies for promoting solidarities and resistance. Such studies also generally oriented toward theoretical and methodological frameworks that privilege the voice of PWD and foster collaborative research relations.

The intersection between community psychology and disability studies as two fields that share concerns on social change, equity and social justice has been acknowledged (Balcazar & Suarez-Balcazar, 2017; Goodley & Lawthom, 2005, 2006; McDonald et al., 2017; White, 2010). However, there remains a challenge for community psychology to generate a better understanding of “disability as an element of human diversity and the role of power in self-society interactions from the perspective of those with firsthand experience” (McDonald et al., 2007, p. 146). Aiming to address such a challenge, therefore, I focus this current study on exploring the meanings and significance of participating in a disability organisation from the vantage point of its members. The following section discusses the history and development of disability organisations and how these organisations have influenced the political struggle of PWD.

## **2.4. Disability Organisations as Sites of Resistance**

Internationally, the politicisation of disability issues has driven the emergence of social movements that has changed the way disability is constructed and responded to (Campbell & Oliver, 1996; Goodley, 2011; Oliver, 2009; Oliver & Zarb, 1989). As noted by Goodley (2011):

The Disabled People's Movement has revolutionised global understanding of disability. By raising the personal experience of disabled people as the primary source of knowledge and identifying disability as a social problem that should be addressed by socio-political interventions (p. 3)

The disability movements in the USA and UK are two examples that demonstrate how through organised political action, activists and scholars have contributed in shifting the ways disability issues are addressed in the societies. For instance, in USA, the emergence of disability movements has driven the legalisation of disability acts and the promotion of human rights-based approach to disability (Pfeiffer, 1993). In the UK, similar movements have led to the development of a national disability organisation, which is led and run by PWD. Such an organisation has challenged the previous patronising practices in which disability organisations were mainly managed by non-disabled people and oriented toward charity-based activities (Campbell & Oliver, 1996; Oliver, 2009; Oliver & Zarb, 1989).

Studies have suggested that the history and development of disability movements varies across countries reflecting the particular social and cultural context in which the movements have been developed (Goodley, 2011; Marks, 1999). Despite the different orientations and strategies found across countries, the emergence of politically oriented disability movements has brought a similar effect in promoting the development of disability organisations, which are led and run by PWD (Blackmore & Hodgkins, 2012). Generally known as Disabled People's Organisations (DPOs), such organisations have contributed significantly in forging strategic solidarities and alliances between disability activists thereby

“challenge the isolation and increase the strength and pride of disabled people” (Marks, 1999, p. 3). The development of DPOs has become a milestone in the political struggle of PWD in the majority of the world, including Indonesia (Yulianto, 2011).

The emerging of DPOs has transformed the political struggles of PWD in at least two significant ways. Firstly, DPOs have enabled PWD to have social and political mediums through which they can assert their authentic voices and agency. Previously, the voices and agency of PWD were generally dismissed as disability organisations were mainly controlled by non-disabled people (Blackmore & Hodgkins, 2012; Campbell & Oliver, 1996; Oliver, 2009). Secondly, DPOs have enabled PWD to counter the dominant pathologising and tragic views of disability by representing themselves as active political actors. Such representations have contributed in demystifying the patronising portrayals of PWD as helpless, unfortunate and dependent individuals (Blackmore & Hodgkins, 2012; Campbell & Oliver, 1996; Dowse, 2001; Oliver, 2009). Through their participation in DPOs, PWD have gained opportunities to assert their identity as subject with rights and contested the negative representation of PWD as object of charity, medical interventions and social protections (Mackelprang & Salsgiver, 2015)

By functioning as alternative social and political vehicles, the emergence of DPOs has transformed the struggle of PWD and the way disability is constructed in societies (Blackmore & Hodgkins, 2012; Campbell & Oliver, 1996; Dowse, 2001; Oliver, 2009). Through DPOs, disability activists and scholars have contributed in generating new discourses and debates on disability, such as through the proliferation of critical political slogans including ‘rights not charity’ and ‘nothing about us without us’ (Blackmore & Hodgkins, 2012). In other words, “DPOs represent the creation of new political, social and artistic bodies, with discourses that give impairment the opportunity to be reimagined, viewed

as resourceful, and endowed with economic, cultural and social capitals” (Blackmore & Hodgkins, 2012, p. 81).

By enabling PWD to generate alternative meanings of and approaches to disability, DPOs have been considered as potential sites of resistance. For instance, Blackmore and Hodgkins (2012) argue that:

... the actions and achievements of DPOs can be read as resisting and countering disability oppression, as well as being part of the production of both emancipatory and disciplinary power. These are not just grand ideas, such as the social model or legislative change, but also in the personal moments of acceptance and pride about impairment that DPOs work constantly to communicate their daily work (p. 76)

The excerpt above suggests that the value of DPOs as sites of resistance is not only related to its political implications, but also to its transformative functions. While studies have highlighted the significance of DPOs as a form of political movement (e.g., Blackmore & Hodgkins, 2012; Campbell & Oliver, 1996; Oliver & Zarb, 1989; Oliver, 2009), little is known about the processes and mechanisms through which participation in DPOs may facilitate the personal and collective transformation of PWD. It is this gap that encourages me to make a contribution by bringing the notion of empowering settings into the discussion. The notion of empowering settings may help to explicate the socio-psychological processes and mechanisms through which the participation of PWD in DPO may be experienced as a transformative process.

Examining the socio-psychological meanings and significance of DPOs is valuable for understanding how changes at the individual level can lead to collective acts of resistance. As argued by Oliver (2009), the politicisation of disability requires consciousness changes at the individual level by transforming personal experiences into political issues:

... at the collective level disabled people may ‘false consciously’ believe that the difficulties they face are because of their individual impairments. Hence they, ‘internalise oppression’ (Sutherland, 1981; Morris, 1991) by believing that it is their fault that they cannot get a job, use public transport, and so on. Second, social and

individual transformations are inextricably linked. However, in materialist theory individual must transform themselves through collective action, not be transformed by others who know what's best for them or what's best for society (p. 102).

Oliver's argument points to the importance of consciousness raising as a prerequisite for promoting changes at the individual level. In addition, his argument suggests that consciousness raising requires one's involvement in collective action. In this regard, Oliver's argument is in line with a question that has become a particular interest of community psychology, that is the question about the role of settings in facilitating social transformation (Aber et al., 2011; Rappaport, 1987; Seidman & Capella, 2017). In the field of community psychology, this question has developed discussions on the notion of empowering settings. I examine further this notion in the following sections.

## **2.5. Empowering Settings**

I start this section by examining some influential theories, which are relevant to explaining the development of empowering settings as a major concept in the field of community psychology. Next, I review the concept of empowering settings itself and how it may function as a potential theoretical framework for the present study.

### **2.5.1. Ecological perspectives and the importance of social settings.**

The concept of empowering settings reflects the importance of social settings as a focus of inquiry in community psychology (Seidman & Capella, 2017). Sarason (1972) defined settings as “any instance in which two or more people come together in a new relationship over a sustained period of time in order to achieve certain goals” (p. 1). Settings can range from something as simple as a family unit to something with more complex social arrangements like society.



Underpinning community psychology's emphasis on the importance of social settings as foci of research and intervention is its orientation toward ecological understandings of human behaviours (Aber et al., 2011; Seidman & Capella, 2017). It is this orientation toward ecological perspectives that has differentiated community from traditional psychology, which mainly views human functioning as a product of intrapersonal factors. Countering this traditional view, community psychology assumes that human functioning reflects the dynamic interactions between individuals and their environments (Kloos et al., 2012; Nelson & Prilleltensky, 2010).

According to Trickett (1996), the emergence of contextualism as a philosophy of science has contributed in shaping community psychology's orientation toward ecologically situated knowledge. Contextualism as a philosophy of science assumes that knowledge always reflects the culture and context in which it is produced, and therefore, "this underscore the possibility that much of social science knowledge may be particular, not universal" (Trickett, 1996, p. 398). Informed by such a paradigm, the development of community psychology as a field of study has been characterised by its focus on understanding individuals' behaviours in particular socio-cultural contexts (Trickett, 2009).

Drawing on the ecological perspectives on human behaviours, community psychology assumes that individuals' wellbeing and problems are resulted from "the transactions between individuals with varied cultural histories, skills, resources, and personal predicaments and the opportunities, resources and constraints of the social contexts of relevance to them" (Trickett, 2009, p. 396). Such an assumption implies that individuals' experiences and how these may positively or negatively affect their quality of life are context dependent. As a result, community psychology has been interested in developing theoretical approaches that can explicate the reciprocal interactions between people and their social environments (Bond et al., 2017a; Kloos et al., 2012; Nelson & Prilleltensky, 2010).

A number of influential theoretical frameworks have contributed to the development of ecological perspectives in community psychology. These frameworks have become the foundations for a range of concepts that highlight the embeddedness of people in context, including the concept of empowering settings. Some of these theoretical frameworks are Kelly's (1969) ecological theory, Barker's (1968) theory of behaviour settings, Bronfenbrenner's (1979) ecological systems theory, Sarason's (1974) theory of psychological sense of community, and Rappaport's (1981) empowerment theory. Each of these theoretical frameworks has provided a distinct conceptual analysis that helps to explicate person – environment interactions.

Kelly's (1969) ecological theory proposed four interrelated principles (i.e., interdependence, cycling of resources, adaptation, and succession) that may explain how people can adapt effectively to different social environments. With these four principles, ecological theory has contributed in explicating how different parts of an eco-system are interconnected in creating resources and circumstances that may facilitate or constrain the development of people's adaptive functioning (Nelson & Prilleltensky, 2010). This theory has further highlighted the contextual nature of human functioning by implying that each social context has its own understandings and criteria of an adaptive behaviour (Jason et al., 2016).

Similar to Kelly's theory, Bronfenbrenner's (1979) ecological system theory proposed a comprehensive model that describes the interconnections of multi-level systems which may have direct or indirect influences in shaping individuals' development. This theory has contributed in mapping out layers of contexts that may shape people's multiple and complex social realities (Neal & Neal, 2013). According to Bronfenbrenner (1979) these layers of contexts include the microsystems (i.e., individuals' immediate social settings such as families and peer groups), the mesosystems (i.e. a social context that host the interactions of different micro systems, such as schools and workplace), and the macrosystems (i.e., the

broader social contexts that encompass all the other systems, such as community, society and culture). Through this conceptualisation, ecological system theory has challenged the traditional perspectives of individuals' development, which tend to dissociate people's functioning from their ecological context (Neal & Neal, 2013).

Barker's (1968) theory of behaviour setting is another conceptual framework, which has contributed significantly in developing community psychology's conceptualisation of person and contexts relations. With this theory, Barker proposed 'behavior setting' as the basic unit of analysis to explore the dynamic interactions between persons and their environments (Hawe, 2017; Perkins, Burns, Perry & Nielsen., 1988). Behaviour settings are basic social units with particular physical, behavioural and temporal arrangements, which host regularised patterns of interactions through which specific types of behaviour may be fostered or inhibited. Examples of such settings include classrooms and religious-based collective activities (Hawe, 2017; Perkins et al., 1988). With his behaviour setting theory, Barker has challenged the common approaches applied in traditional psychology, which tends to position individuals' behaviours as the focus of analysis. As argued by Perkins et al. (1988), this theory has contributed in identifying a basis unit of analysis that enables researchers to assess human behaviour on situational and community levels.

In addition to the previous theoretical frameworks, the development of ecological perspectives in community psychology has been further extended by Sarason's (1974) theory of psychological sense of community and Rappaport's (1981) theory of empowerment. These two theories have often been identified as the defining features of community psychology. While Kelly's (1969), Bronfenbrenner's (1979) and Barker's (1968) theory have enabled researchers to identify the components of people's social ecology, Sarason's (1974) and Rappaport's (1981) theories have made its distinct contributions by exploring the psychological aspects of a social setting. Both theories are particularly concerned with the

question of how people experience their social environments and how this may impact on their personal and collective wellbeing (Jason et al., 2016).

Psychological sense of community (PSOC) refers to a feeling of similarity, connection and interdependence that one shares with others who are part of their significant social environments (Sarason, 1974). As a theoretical construct, PSOC has enabled researchers to explicate the ways people interact with their social environments and how this contributes in defining their identity, source of supports, as well as their personal and social wellbeing (Bess, Fisher, Sonn & Bishop, 2002). McMillan and Chavis (1986) further developed Sarason's idea by proposing four elements of PSOC, which include membership, influence, fulfillment of needs, and shared emotional connection. PSOC theory has made extensive contribution in developing community psychology's ecological perspective by enabling researchers to investigate people's experiences in various types of social groups, from territorial-based groups such as neighbourhood associations to interest-based and politically-constructed groups such as religious and immigrant communities (Fisher, Sonn & Bishop, 2002).

Community psychology is a field of study, which is characterised by its commitment to work with marginalised individuals and groups to tackle the unjust systems and practices that have produced their oppressive realities (Kloos et al., 2012; Nelson & Prilleltensky, 2010). Therefore, in its attempts to understand the dynamic interactions between persons and their social environments, community psychology has been particularly interested in the question of how and what types of social settings that may promote the ability of marginalised individuals and groups to transform their disadvantaging living conditions (Rappaport, 1987). Rappaport's (1981) theory of empowerment is one of the most influential theories in community psychology that have addressed this question.

Rappaport (1981) defined empowerment as a process and mechanism by which people or groups gain access to resources and mastery that enable them to tackle their adversities. With its focus on understanding the experiences of marginalised individuals and groups, empowerment theory has further expanded community's psychology orientation toward ecological perspectives of human behaviour. This theory has particularly enabled researchers to explore the processes and mechanisms through which particular social environments may produce and sustain people's experience of marginality, as well as how these may facilitate resistance and contestation (Rappaport, 1987; Zimmerman, 2000). In addition, by constructing empowerment as both a product and response to particular social contexts, this theory has further underlined the importance of applying contextual approaches to understand human functioning (Jason et al., 2016).

In line with Sarason and Rappaport, other scholars in the field of community psychology have further developed theoretical frameworks, which are focused on exploring the ways people perceive, experience and give meanings to their social environments. One of such theoretical frameworks is the activity setting theory as proposed by O'Donnell, Tharp and Wilson (1993). According to this theory, the dynamic interactions between individuals and their social environment can be best understood by investigating the subjective meanings that people ascribes to their interactions with other individuals in a particular setting (Hawe, 2017; Kloos et al., 2012). Therefore, this theory suggests the importance of shared activities as the basic unit of analysis for community psychology research and practice. Investigating people's participation in a shared activity allows researchers to uncover how a particular setting facilitates the development of intersubjectivity (O'Donnell & Tharp, 2012; O'Donnell et al., 1993). O'Donnell et al. (1993) defined intersubjectivity as a sense of commonality as a result of having a shared belief, values, assumptions and experiences.

This review outlines how the emphasis on ecological understanding of human behaviours has evolved in community psychology theories. All of these theories underline the importance of studying human functioning in its relevant social settings. The concept of empowering settings has been developed as part of such an emphasis. This concept is detailed in the following section.

### **2.5.2. The concept of empowering settings.**

The notion of empowering settings reflects the ecological understanding of empowerment as a contextual and interactive process. In this sense, the notion of empowering settings assumes that empowerment requires people's participation in collective processes within a particular social arrangement or setting (Aber et al., 2011). As argued by Rappaport (1987), embedded in the concept of empowerment is "a quality of the relationship between a person and his or her community, environment, or something out-side one's self" (p. 130). He suggests that studies on empowerment need to investigate the settings of these relationships and how the settings facilitate or impede empowerment. Case and Hunter (2012) propose a similar idea through their study on the processes and mechanisms whereby people develop adaptive responses to oppression and marginalisation. They argue that adaptive responding requires people participation in settings as it needs "the presence of strategic others" (p. 261).

The term empowerment itself is defined as "an intentional ongoing process centred in the local community, involving mutual respect, critical reflection, caring and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group as cited in Perkins & Zimmerman, 1995, p. 570). This definition reflects the social nature of empowerment. Although it can be experienced as an "individual-level construct", empowerment is rooted in participative processes through which people gain control and critical awareness from their

interactions with other individuals (Zimmerman, 2000, p. 59). The investigation of the characteristics of empowering settings is, therefore, crucial for understanding the connections between participation and empowerment. Rappaport (1987) highlighted this point by stating:

Thinking about the definitions of empowerment suggests that we need to research the phenomena by studying how empowerment is actually experienced by those individual people who express the sense that they are, and are not, in control of their own lives, and by studying the mediating structures in which they reside. That is, in addition to a focus on professionals creating programs, we need to study people in settings that are a part of their ongoing life (p. 135)

The importance of settings as a catalyst of social changes has been long emphasised in the field of community psychology. Driven by an ecological perspective on human functioning, community psychology research has extensively investigated the role and mechanisms of settings in promoting or inhibiting people's liberation and well-being, both at the personal and communal level (Aber et al., 2011; Nelson & Prilleltensky, 2010).

Underlying community psychology's emphasis on the importance of settings is the 'person environment fit' assumption that highlights the determining role of social system in shaping human development (Kloos et al., 2012; Nelson & Prilleltensky, 2010). This assumption proposes that to reach their full potential people should be in an environment that best meets their needs. Therefore, it becomes a particular interest of community psychology to understand how social systems work in particular settings and how these facilitate the expected social changes. This interest has generated a significant body of research that examines community organisations (e.g., self-help groups, neighbourhood associations, voluntary communities) as settings that have empowering effects for marginalised individuals and groups (e.g., Aber et al., 2011; Case & Hunter, 2012; Maton & Salem, 1995; Maton, 2008; Peterson & Speer, 2000).

Maton (2008) defines empowering community settings as a social space with enabling characteristics and processes that over an extended period of time may generate empowering outcomes. He argues "empowering community settings are distinctive in their potential to

simultaneously contribute to individual development, community betterment, and positive social change” (p. 5). The importance of studying empowering settings lies in its potential to explicate “how change actually occurs in practice and how transformation might realistically be facilitated” (Kesby, 2005, p. 2049). A better understanding of the processes and mechanisms of empowering community settings is considered crucial as it may generate insights in how as practitioners, community psychologists can better facilitate the development of empowering community settings (Aber et al., 2011).

The significance of empowering community settings is also related to its role as the mediating structures between the larger socio-historical and political contexts and people’s everyday life as a community (Aber et al., 2011; Rappaport & Simkins, 1991). Hence, researching empowering community settings may explicate the reciprocal interactions between individuals and the larger social systems. Such studies may explain how an oppressive system is operated and experienced and at the same time reveals how as a group, individuals disrupt or resist the oppression (Maton, 2008).

The interest in understanding the role of settings as a catalyst of social transformation has generated a body of research, which is focused on identifying the characteristics and mediating variables that define empowering community settings. There are various other terms that have similar definitions with the notion of empowering settings. Some of them are: alternative settings (Cherniss & Deegan, 2000; Dalton, Elias & Wandersman 2007), free spaces (Fine, Weis, Centrie & Roberts, 2000) and sites of resilience (Payne, 2011). Despite the different terminologies used, these notions describe similar characteristics that define settings as a transformative site. Based on in-depth, multilevel, longitudinal studies on three different community settings, Maton and Salem (1995) theorise that empowering community settings are generally characterised with:



(a) a belief system that inspires growth, is strengths-based, and is focused beyond the self; (b) an opportunity role structure that is pervasive, highly accessible, and multifunctional; (c) a support system that is encompassing, peer-based, and provides a sense of community; and (d) leadership that is inspiring, talented, shared, and committed to both setting and members (p. 631).

In addition to the four characteristics above, Maton (2008) argues that empowering community settings generally have core activities, which are engaging and facilitating active learning. Through such activities, members are enabled to develop reflective understandings and critical awareness of the social realities shaping their living conditions. Also, he suggests that empowering settings typically have relational environment, which are supportive, caring, and nurturing sense of community.

A number of studies have indicated the applicability of the characteristics mentioned above in various community organisations, including in territorial-based organisations such as neighbourhoods and residential groups (e.g., Mok, 2004; Nelson, Pancer, Hayward & Kelly, 2004; Peterson & Reid, 2003), as well as in interest-based organisations such as peer-support groups (e.g., Davidson et al., 1999; Nelson, Lord & Ochocka, 2001; Peterson & Speer, 2000; Stanton-Salazar, 2011). These studies indicate that although sharing similar basic characteristics, each empowering community setting usually has specific features that signify its role as an enabling environment. For example, comparing three types of community organisations, Peterson and Speer (2000) found that each organisation emphasises different organisational characteristics to enact its function as a transformative site. Such a variety suggests that studies on empowering community settings need to be sensitive with the particularity of each setting. Maton and Salem (1995) highlighted this point with the notion of ecological specificity that refers to characteristics that are unique to a setting. They recommended that research on this topic needs to focus simultaneously on “ecological specificity and ecological commonality across types of empowering settings” (p. 11).

## **2.6. Empowering Settings: How Do These Empower?**

The importance of empowering settings as a vehicle for social change has been well supported. However, there remains a gap in understanding how the reciprocal interactions between individuals and settings can generate empowering outcomes (Seidman & Capella, 2017). As argued by Case and Hunter (2012), future research on this topic need “to further think critically about the ways in which contexts promote psychological well-being for those who experience oppression” (p. 268). A number of theoretical frameworks provide potential concepts to explore the links between participation and empowerment. These theoretical frameworks include *community narrative*, *social representations* and *counterspaces*. Each is discussed in the following sections:

### **2.6.1. Community narrative.**

A narrative approach to empowerment is informed by an assumption that human beings organise their experiences and make sense of the world in the form of a narrative (Johnstone, 2004; Rappaport, 1995, 2011). In this sense, a narrative does not only represent human cognitive functioning, rather, it constitutes what is perceived and experienced as social, cultural, and political realities (Bruner, 1991; Hyvärinen, 2008). Narratives – which can be in the form of stories, myths, texts, rituals and other symbolic systems – have powerful effects in directing behaviour as they give meaning to individuals’ experiences and their living environment. As Rappaport (1995) puts it, narratives “tell us not only who we are but who we have been and who we can be” (p. 796).

Narratives are central to identity construction, both in terms of individual and collective identity. Through narratives, the social ideas, beliefs and values that govern a society are operated and propagated to its members. Hence, as noted by Somers (1994) “all of us come to be who we are (however ephemeral, multiple, and changing) by being located or

locating ourselves (usually unconsciously) in social narratives rarely of our own making” (p. 606). Driven by such an understanding, therefore, a narrative approach to empowerment argues that altering social narratives is a potential strategy to promote social changes (Rappaport, 1995). In this sense, a narrative is both a resource and target of social change.

Drawing on narrative approaches, empowering community settings can be understood as a site for people to understand and reflect on “how community and organisational narratives are created and appropriate into our personal life stories (and vice versa) and how these stories influence identity and behavior, personal and social change” (Rappaport, 1995, p. 796). Specifically, in regard to those who are oppressed and marginalised, a narrative approach to empowerment is about gaining critical awareness of dominant cultural narratives, which create and sustain the oppressive realities for those who do not belong to the powerful groups (Rappaport, 1995; Salem, 2011).

A dominant cultural narrative consists of widely available stories, which are continuously reproduced by those who are in power to maintain the hierarchy in a society (Rappaport, 2000). Demeaning stereotypes and jokes about minorities are examples of how dominant narratives are reproduced and maintained. Those who are privileged by dominant narratives usually maintain their position by normalising or rationalising such narratives. As a consequence, there is a systemic pressure for the marginalised to internalise and appropriate dominant narratives as part of their own personal life story. Within narrative frameworks, therefore, an empowering process requires mechanisms through which people can challenge and disrupt dominant narratives. Also, new shared narratives need to be created as a source for liberating personal life stories and identities (Hammack, 2008, 2011; Rappaport, 1995, 2000). In this sense, narratives are not just a form of communication, they are more than that: “a resource for dominating others, for expressing solidarity, for resistance and conflict” (Johnstone, 2004, p. 644).

As narratives are socially constructed, creating empowering shared narratives requires a collective process. As argued by Rappaport (1995), “change cannot be sustained in the absence of a group that supports that change, in part through the experience of a shared community narrative” (p. 804). This explains how empowering community settings function as a link between participatory processes and empowerment. By participating in a setting, people can have conversations about the existing community narratives and how those narratives have shaped their experiences. The conversations may generate critical awareness of the processes and mechanisms through which particular narratives are valued while others are rejected. Such an understanding may foster new ways of thinking about people’s oppressive experiences and stimulate the emergence of more empowering shared-narratives (Rappaport, 1995).

A number of studies have further explored the potential of settings as a supportive context for developing alternative narratives. For example, a study by Nelson et al. (2001) shows that for individuals with mental health issues, empowerment involves resistance to the internalisation of the dominant narrative that portrays mental health issues as impairment. Participation in community mental health organisations facilitates this process by creating opportunities for the individuals to engage in activities that increase their confidence and self-esteem, their control over daily life, and their independence. In this sense, participation in an empowering setting provides a supportive context for the individuals to “reconstruct personal stories that reflect mental health, strengths, and hope, as an alternative to the dominant social narrative of people with mental health problems as dangerous psychos” (p. 139).

Studies on other types of social groups also reported similar findings in relation to how settings may foster the development of empowering shared narratives. These include studies on spiritually-based communities (e.g., Mankowski & Rappaport, 2000; Maton, 2000; Mulvey, Gridley & Gawith, 2001), alcohol anonymous groups (e.g., Humphreys, 2000;

Weegmann & Piwowoz-Hjortb, 2009) and disability groups (Harter, Scott, Novak, Leeman & Morris, 2006; McDonald et al., 2007). These studies suggest that collective narratives are powerful resources for identity development and changes. Participation in a setting is a vital factor that mediates “the appropriation of shared narratives into one’s personal life story on the one hand, and the creation of new narratives or modification of existing narratives (social change) on the other” (Rappaport, 2000, p. 5).

### **2.6.2. Social representations.**

Social representation theory explores the ways whereby everyday knowledge, belief and practices are constructed and how these influence people’s attitudes and behaviours (Purkhardt, 2015; Sammut, Andreoulli, Gaskell & Valsiner, 2015). This theory is similar to narrative psychology for the interest in understanding how people make sense of the world. In addition, the two theories are concerned with the role of everyday commonsense in establishing and preserving stigmatising practices and how such practices affect people’s identity and wellbeing (Howarth, Foster & Dorrer, 2004; Murray, 2002). For instance, several studies have utilised social representations theory to investigate the dominant representations of disability as a form of personal inferiority and how such a representation has contributed in constructing the otherness of PWD (e.g., Ferrucci & Cortni, 2015; Harma, Gombert & Roussey, 2013)

According to Jodelet (as cited in Howarth, 2006), social representations are defined as “images that condense manifold meanings that allow people to interpret what is happening; [and] categories which serve to classify circumstances” (p. 67). Thus, similar to narratives, social representations of an object or event are not only a tool for communication and understanding. More than that, social representations construct social realities and direct intergroup interactions (Howarth, 2001, Purkhardt, 2015). Zavalloni (1993) referred to social

representations as a ‘relational weapon’ (p. 6) as these can function to defend a group’s interest. Social representations of an idea, object or event are often created to serve a particular economic or political agenda. In the context of marginalisation, social representations can be a symbolic tool to rationalise or even institutionalise unjust practices that benefit those who are privileged by hegemonic social representations. Therefore, contesting or challenging social representations are necessary for creating social changes (Flick, 1995; Howarth, 2001, 2006; Purkhardt, 2015).

Social representations are a lens through which people understand and give meaning to their experiences (Campbell & Jovchelovitch, 2000). Social representations can be very powerful in directing the way people perceive their world. For this reason, Campbell and Jovchelovitch (2000) highlighted the potency of social representations in explaining the connection between participatory processes and empowerment. They argued that the process of participation may give people an opportunity to express, reaffirm and if necessary, re-negotiate social representations of their world. Howarth, Andreouli & Kessi (2014) shared a similar argument. They stated that social representations:

“[P]rovide the lens through which to view and create social and political realities, mediate people’s relations with these socio-political worlds and defend cultural and political identities. Social representations are therefore key for conceptualising participation as the activity that locates individuals and social groups in their socio-political world” (p. 19)

For those who are disadvantaged, a participatory process can be a route to challenging the social representations that construct their oppressive realities (Campbell & Jovchelovitch, 2000). In this sense, the notion of empowering community settings can be considered as a potential space for people to foster collaborative resistance against marginalising representations. Through such a process people create possibilities for disrupting the stigmatising representations of minorities as deviant others. This act of resistance can only be developed in a community of others (Howarth et al., 2004; Howarth, 2006). As argued by

Howarth (2006), participation in social groups and community networks can facilitate people to have critical awareness on how representations pervade particular social practices by addressing the following questions:

How do these images and categories come into our interpretations? Why do we use some representations instead of others? Is it possible to have conflicting representations? Do some people have more power to impose 'their' representations onto others? If so, can these representations be resisted? What is the relationship between representations and 'the concrete reality'? What is the relationship between representations and the social order? Can representations be used to defend or challenge the social order? (p. 67)

The quotation above suggests that social representations are powerful resources, either for validating stigma or amplifying resistance. For example, in the case of HIV/AIDS, social representations of the infection as the illness of the immoral significantly contribute to perpetuating the stigmatising and discriminative attitudes to those who live with HIV/AIDS (Campbell, Foulis, Maimane, & Sibiya, 2005; Campbell, Nair, Maimane & Nicholson, 2007). However, the negotiating nature of social representations also opens possibilities for those who are disadvantaged by the condemning representations of HIV/AIDS to develop alternative representations that affirm their sense of worth and correct the 'victim-blaming' views on this illness.

Joffe's (1995) research on social representations of AIDS among gay men in the United Kingdom indicates this powerful meaning of alternative representations. In his research, Joffe presented the 'Gay Pride' movement as a powerful setting to contest the hegemonic representation of HIV/AIDS as the illness of homosexuals. By framing HIV/AIDS as an issue of "safe sex practices", this movement has shifted the mainstream view that associate the virus with one's sexual orientation (p. 9). In addition, Joffe's research implies that developing alternative representations requires collective processes in an empowering setting. In the case of gay communities in the UK, the Gay Pride movement is the

empowering setting that facilitates British homosexual people to challenge the hegemonic abnormalising view, as well as to assert their rights and identity.

The research above indicates that social representation is “a potential space for meanings to be contested, negated and transformed” (Howarth, 2006, p. 77). Social representations open possibilities for the oppressed and marginalised to reject victimisation by articulating their position as active agents who construct their version of social realities. Such a process cannot occur in an isolative-individual context. Instead it requires a collective power (Howarth, 2006; Howarth et al., 2004, 2014). In this sense, empowering settings can be considered as a context where people can assert their collective agency to negotiate with the social representations that have shaped their lived experiences.

### **2.6.3. Counterspaces.**

The term counterspaces refers to social spheres that function as sites for resistance against oppression and marginalisation. Solorzano, Ceja and Yosso (2000) use the term counterspaces specifically in the context of racial discrimination. They define counterspaces as a site where the subjugating views imposed on the racially marginalised people are challenged and positive identity are nurtured.

Developing this notion further, Case and Hunter (2012) propose counterspaces as “settings, which promote positive self-concepts among marginalised individuals (e.g., racial and sexual minority individuals, persons with disabilities, etc.) through the challenging of deficit-oriented dominant cultural narratives and representations concerning these individuals” (p. 261). In such settings, proactive strategies are created to disrupt the internalisation or reproduction of oppressive narratives and representations.

Drawing on this understanding, counterspaces can be understood as a setting that fosters personal and collective processes through which people can resist the oppressive



systems they experience. In this sense, participation in such settings facilitates people to question the unjust systems and practices, which otherwise have been normalised and perceived as unchangeable realities (Case & Hunter, 2012). It is through the interactions with other individuals who have similar experiences that the questioning process is nurtured. Case and Hunter (2012) suggest, “all counterspaces share the same functional mechanisms whereby they challenge the negative representations and notions concerning one or more marginalized identity” (p. 262).

Underlying the concept of counterspaces is an assumption that oppression and marginalisation are operated through the process of stigmatisation (Case & Hunter, 2012, 2014). In this sense, counterspaces is about creating collective mechanisms that enable people to contest the stigmatising identities imposed upon them. Case and Hunter (2012) theorise that the empowering mechanisms of counterspaces are manifested through three processes namely: (a) narrative identity work, (b) acts of resistance and (c) direct relational transactions.

Narrative identity work refers to a process in which setting members intentionally create and maintain an alternative narrative to challenge the dominant narrative that frames them as defective and problematic groups (Case & Hunter, 2012). Alternative narratives are generally created and preserved to serve two functions. Firstly, such narratives are created to recognise the oppressive realities of setting members, which are usually ignored or denied by the dominant narrative. Secondly, alternative narratives function as restorative mechanism by promoting stories and images, which affirm setting members’ strength and resilience to overcome oppression (Case & Hunter, 2012). Alternative narratives are a powerful resource for individuals to envisage transformative and liberating personal narratives (Case & Hunter, 2012, 2014).

Case and Hunter (2012) argue further that the empowering meanings of alternative narratives are usually represented through the acts of resistance. Through the acts of

resistance, alternative narratives are embodied and acted out. These can be in the form of collective rituals, arts work, or endorsement to particular behaviours (e.g., clothing styles, language forms). Lastly, Case and Hunter (2012) suggest that both narrative identity work and the acts of resistance require a certain type of relational environment as the underpinning process. They use the term direct relational transactions to refer to a type of social interactions that promote empathy and support among those who share similar experience of oppression.

To some extent, the notion of counterspaces as proposed by Case and Hunter (2012) reproduce prior discussions about the relation between persons and settings. Each key idea that builds this notion (i.e., narrative identity work, the acts of resistance and direct relational transactions) has been developed as a conceptual framework on its own and has generated a separate body of research (e.g., Campbell & Deacon, 2006; Howarth, 2004; Mankowski & Thomas, 2000; Salzer, 1998; Speer & Hughey, 1996; Wilke & Speer, 2011). The contribution of the concept of counterspaces is in its attempt to theorise the interrelation between those key ideas and how it may explain the links between participatory settings and empowering outcomes. A number of studies in the field of education have supported the potential of counterspaces as a concept that may explain how settings can act as an empowering site (e.g., Carter, 2007; Cerezo & Bergfeld, 2013; Grier-Reed, 2010; Lavie-Ajayi & Krumer-Nevo, 2013; Schwartz, 2013; Shalhoub-Kevorkian, 2005).

An example of studies that explore the notion of counterspaces, is a research by Lavie-Ajayi and Krumer-Nevo (2013). Their study shows how participation in a program called “In a Different Mindset” can facilitate young people to challenge the notion of “youth at risk” as a stigmatising label. This program is developed based on an understanding that the label “youth at risk” ignores the structural injustice that may have caused young people’s marginalisation. This label attributes young people’s difficulties to their personal characteristics. The program provides a setting for youth workers and the participants to engage in critical conversations

that challenge the hegemonic views of youth workers as the corrective force. The engagement in this setting enables both the youth workers and the participants to counter the narrative of criminality with a new narrative that is focused on hope and sense of worth.

Cerezo and Bergfeld (2013) argue for a similar point of view in the context of addressing the victimisation of LGBTQ youth in the school context. Reviewing the program called Gay-Straight Alliance (a program targeted to tackle discriminations against LGBTQ students), they suggest that this kind of program can function as a counterspace to deal with the abnormalising views on non-heterosexual students. These studies on the notion of counterspaces confirm the importance of alternative settings for those who are oppressed or marginalised. Participation in such settings create possibilities for acknowledgment, solidarity and liberation from the stigmatising worldviews.

## **2.7. Disability Organisations as Empowering Settings**

It has been theorised that participatory approaches may facilitate social transformation that leads to empowerment (Campbell & Jovchelovitch, 2000; Kesby, 2005; Rappaport, 1987). However, the processes and mechanisms through which participation results in empowerment still need further investigation. This chapter explores the idea of empowering settings as the bridging concept that links participation and empowerment. Particularly in the context of disability studies, disability organisations appear to be a potential site for exploring the notion of empowering settings as these organisations may function as sites of resistance for PWD (Blackmore & Hodgkins, 2012).

Investigating people's participation in disability organisations may generate a better understanding of a question, which is central to community psychology that is the question about the role of settings in promoting the wellbeing of marginalised individuals (Aber et al., 2011; Maton & Salem, 1995; Maton, 2008; Seidman & Capella, 2017). Such a study may

explicate the pathways and processes through which disability organisations may function as a catalyst for social changes, in relation to the struggle of PWD for equality and social justice.

Disability organisations as sites of resistance are generally characterised by their orientation toward practices, which seek to liberate PWD from their oppression (Blackmore & Hodgkins, 2012). However, the nature of disability organisations as liberating social settings is generally varied from place to place, depending on the specific socio-historical, cultural and political context in which the organisations exist (Goodley, 2011; Marks, 1999). Different contexts will most likely generate different views of and approaches to disability, therefore, require strategies and responses, which are specific to those contexts (Fougeyrollas & Beauregard, 2001). This understanding underlines the importance of studying the nature of disability organisations as liberating social settings in different socio-historical, political and cultural context, as argued by Barnes and Mercer (2003):

In order to grasp the meaning and significance of impairment, how and why individuals are considered ‘abnormal’ or ‘incompetent’, and how control is exercised and resistance becomes manifest, it is illuminating to explore these issues within different cultural contexts (pp. 135 – 136).

This understanding of disability organisations as contextual settings is in line with the notion of ecological specificity in the studies of empowering settings (Maton & Salem, 1995). While there are general features, which characterise empowering settings, the particularity of each setting may generate specific processes and mechanisms.

Disability studies in Indonesia have not been widely pursued (Yulianto, 2011). The scarcity of disability research (especially those which adopt critical perspectives) reflects the pervasive discrimination and marginalisation commonly experienced by PWD in Indonesia. In the last 10 years, with the emerging disability movements, there have been growing attempts to advance disability studies in Indonesia (e.g., Lusli et al., 2015; Suharto, 2011, 2016; Tsaputra, 2016; Yulianto, 2011). An example of such studies is Yulianto’s (2011)

research that investigates the role and significance of local disability organisations in shaping the landscape of disability activism in Indonesia. However, there have been limited empirical investigations that explore the socio-psychological meanings and significance of disability organisations for the participating individuals.

In this current study, I aim to address this gap by investigating people's participation in a local disability organisation. Drawing on the notion of empowering settings, I particularly want to explore the socio-psychological processes and mechanisms, which have characterised this local disability organisation as an enabling social setting. By undertaking this current study, I aim to contribute in expanding the discussion about the link between participation and empowerment, particularly in relation to the struggle of PWD for equality and social justice. A detailed analysis on the collective processes and mechanisms that take place in a local disability organisation may promote a deeper understanding of how such an organisation may function as a transformative social site in the Indonesian socio-historical and political context. In addition, this analysis may also generate situated and contextual knowledge on empowerment.

## **2.8. Chapter Summary**

Understanding how social changes actually occur in practice and can be realistically facilitated is a particular interest of community psychology. Developing such an understanding is crucial considering the commitment of community psychology to work with those who are oppressed and marginalised, and advocating the values of equality, social justice and respect for diversity (Bond et al., 2017a; Rappaport & Seidman, 2000).

The notion of empowering settings is a potential concept to investigate the nature of social changes, particularly in regard to the struggle of the disadvantaged groups in resisting their oppression and marginalisation. This concept provides a fertile ground to discuss how

participation in a social setting may facilitate empowering processes and outcomes that enable people to collectively transform their unjust living condition. In regard to the issue of disability, the notion of empowering settings is a potential concept to investigate the nature of disability organisations as sites of resistance for PWD.

Literature on empowering settings (e.g., Aber et al., 2011, Maton & Salem, 1995; Maton, 2008; Seidman & Capella, 2017) has suggested that settings are diverse in nature and function. Therefore, as argued by Case and Hunter (2012), settings need to be “understood in their own right” (Case & Hunter, 2012, p. 258). In Indonesia, local disability organisations provide potential contexts to further explore the notion of empowering settings. The development and significance of local disability organisations as a political movement have been increasingly investigated (e.g., Yulianto, 2011). However, little is known about the socio-psychological processes and mechanisms whereby people’s participation in local disability organisations may generate empowering outcomes. This study aims to address this gap by investigating people’s participation in a local disability organisation in the Bantul District of Yogyakarta Province, Indonesia.

## Chapter 3

### Contextualising the Study

*Empowering settings* and *disability* are the two keywords of this study and as such, require both contextual definition and discussion. The two notions need to be situated within the particular historical, cultural and political context in which the study is undertaken. I include two main discussions in this chapter. The first part of the chapter describes how disability is situated in the Indonesian society. In the second part, I specifically discuss Javanese culture as the cultural framework, which has significant influence in understanding how disability is constructed in the local community where the disability organisation being studied is located.

#### 3.1. Disability in Indonesia

Indonesia has ratified the United Nations Convention on the Rights of Persons (CRPD) with Disabilities in 2011. Ideally, this ratification might be understood as the fulfilment of the rights of PWD in Indonesia. However, the everyday life of PWD in Indonesia is still mainly characterised by discrimination and marginalisation (Edwards, 2014). In this section, I discuss the common approaches to disability in Indonesia and how these influence the everyday discrimination and marginalisation faced by PWD in areas of law, education, livelihood and social participation. In addition, I outline the emerging local disability organisations in Indonesia and their attempts to promote more progressive approaches to disability.

##### 3.1.1. Disability as an individual and medical problem.

According to the WHO, 15% of the world's population experience some form of disability with the majority of them living in developing countries. However, obtaining

accurate data of disability in developing countries has been identified as an ongoing challenge (Mitra, Posarac & Vick, 2012; WHO, 2011). Indonesia is one such case. Understanding the landscape of disability in Indonesia is hampered by inconsistent disability criteria used by key government agencies along with inadequate population surveys. These have produced statistical data, which might not accurately represent the actual prevalence of disability in Indonesia. A part of the marginalisation that is commonly experienced by PWD in Indonesia is their very exclusion from population surveys (Liu & Brown, 2015; Salim & Syafi'ie, 2015). As a result, official reports on disability tend to present lower disability prevalence than the actual condition. One among only few comprehensive analyses on disability in Indonesia is a study by Adioetomo et al. (2014). This study provides the main reference for the statistical information presented in this chapter.

Using the most recent standards on defining and conceptualising disability (i.e., the International Classification of Functioning, Disability, and Health from WHO), the study by Adioetomo et al. (2014) provided detailed information that was rarely included in population surveys and censuses from Indonesian key government agencies. Their findings suggested that in 2014 the prevalence of disability in Indonesia was between 10% to 15% of the total estimated population (approximately 24 to 37 million people). This number was consistent with the global findings as reported in the 2011 World Report on Disability. According to this report, the prevalence of disability in most countries was approximately 15% (WHO, 2011). Ironically, the 2012 *Survei Sosial Ekonomi Nasional* (A nation-wide socio-economic survey conducted by the Indonesian Central Bureau of Statistics) reported a significantly lower prevalence that was about 2.45% of the total estimated population (Pusat Data dan Informasi Kementerian Kesehatan RI, 2014).

This inconsistent data on disability as described above is one among many problems, which indicate how disability has not been conscientiously addressed in Indonesia. The lack



of government's commitment is often cited as the causative factor (e.g., Irmansyah, Prasetyo & Minas, 2009; Liu & Brown, 2015; Sirait, 2008). However, drawing on the social model of disability, it becomes apparent that the problems of disability in Indonesia may not be necessarily rooted on the political commitments of the government (Thohari, 2007). Instead, the problems are more accurately understood as being underpinned by more fundamental factors, such as the domination of individual and medical perspectives of disability (Adioetomo et al., 2014; Irwanto et al., 2010; Thohari, 2007). With the domination of such perspectives, disability tends to be approached as a personal tragedy or pathology caused by the person's abnormality that needs to be addressed through essentially medical interventions. The idea of disability as a product of problematic and discriminatory social relations, which places PWD in disadvantaged positions, has not been a major part of the public discourse on disability. Consequently, promoting structural changes that cultivate a more just social relationship between PWD and non-disabled people appears still to be a rarity (Suharto, 2011; Thohari, 2007).

The domination of the pathologising approach to disability is reflected in the terms commonly used to describe disability (Irwanto et al., 2010; Thohari, 2007). The use of terms that are more consistent with the social model of disability, such as *disabilitas* (the Indonesian version of disabled) and *difabel* (the preferred term in the Indonesian context to refer to PWD) is a relatively recent development, which are only emerging in the last 10 years (Suharto, Kuipers & Dorsett, 2016; Suharto, 2011). Previously, people were more accustomed to pathologising terms such as *cacat* (impaired or invalid), *kelainan* (abnormal), and *tuna* (lack), such as in *tuna rungu* (deaf), *tuna netra* (blind) or *tuna wicara* (mute). Indeed, the uses of these degrading terms are still quite common although new terms have been introduced (Adioetomo, et al., 2014; Suharto, 2011; Suharto et al., 2016). For example, some public

buildings still use the term “*toilet penyandang cacat*” (toilet for handicapped persons) to sign accessible toilets.

This pathologising approach to disability is even reflected in how some key government agencies frame disability issues. For example, in the organisational chart of the Indonesian Ministry of Social Affairs (MoSA), the disability sector is assigned under the General Directorate of Social Rehabilitation (Direktorat Jenderal Rehabilitasi Sosial, 2013). Within this general directorate, PWD are grouped together with drug addicts, homeless, beggars, prostitutes, ex-prisoners, juvenile delinquents and neglected senior citizens under the category of *penyandang masalah kesejahteraan sosial* (sub-population with social problems). Such a categorisation implicitly reinforces the view of disability as an individual problem, which is caused by the person’s defects (Adioetomo et al., 2014).

With social activists starting to advocate for more critical approaches to disability, there has been an observable gradual change in how government agencies address disability issues (Good, Good & Grayman, 2013; Ratnaningsih, 2016). Some government agencies have begun initiating programmes, which reflect a more empowering approach to disability. The Indonesian MoSA’s involvement in the emerging community-based program for people living with mental health issues is one such example (Stradford et al., 2014). Among the purposes of the program is to stop the common practice of shackling or confining people with mental disabilities (Jenkins, 2016; Schwarz, 2016). However, such a change has not yet been recognised as a mainstream practice. The majority of government programs remain oriented toward an individualised and medicalised approach to disability (Adioetomo et al., 2014).

Although disability is predominantly framed as an individual and medical issue, lacks of adequate and accessible medical supports for PWD are commonly reported (Kusumastuti et al., 2013). For example, as noted by Kusumastuti et al. (2013) the availability of public hospitals with services and facilities that address the specific needs of PWD remains limited

and only available in big cities. Furthermore, the National Health Insurance does not cover costs associated with specific aids needed by PWD, such as assistive devices like wheelchairs, walkers, orthoses and prostheses (Adioetomo et al., 2014; Kusumastuti et al., 2013). The inadequacy of medical services and facilities for PWD was reflected in the 2012 Survey on the Need for Social Assistance Programmes for People with Disabilities (the 2012 SNSAP-PWD). The survey was conducted by the Demographic Institute, University of Indonesia and involved 2,200 PWD from 11 provinces (Adioetomo et al., 2014). The survey found that 85.9% of the respondents (who received national health benefits) needed medical rehabilitation, but only 44.4% received this service. Likewise, in terms of the need for assistive devices, there were 74.4% of the respondents who need such devices, but only 19,8% of them who received the assistance (Adioetomo et al., 2014).

Since disability is mainly viewed as an individual problem, the awareness that disability is a problem caused by disabling social and physical environments has not been part of the everyday understanding of disability (Irwanto et al., 2010; Thohari, 2007). Such a condition is strongly reflected in the issues of accessibility and mobility. For instance, accessible public facilities are very limited, even in big cities, which tend to have the most-developed infrastructure like Jakarta, the capital of Indonesia. Basic public facilities such as accessible footpaths, public toilets and public transport are still a rarity (Darmawan, Woromurtini & Sari, 2014; Liu & Brown, 2015; Sirait, 2008). Back in 2000, the late Indonesian president, Abdurrahman Wahid, who had low vision, launched the National Public Accessibility Movement, however, little has changed since then (Sirait, 2008). For example, in 2013, when Shuaib Chalken, the United Nations Special Rapporteur on Disability visited Yogyakarta (a major city in Indonesia) to assess the realisation of CRPD two years after the ratification, he had to be carried onto the aircraft by the cabin staff because a suitable wheelchair was not available (Natahadibrata, 2013).

As disability is mainly framed as an individual and medical problem, dealing with ‘victim blaming’ attitudes is a common experience for most PWD in Indonesia (Lusli et al., 2015; Yulianto, 2015). Victim blaming attitudes tend to view the marginalisation and discrimination of PWD as the consequences of their abnormality rather than as a product of an unjust and disabling social system (Yulianto, 2015). Such attitudes are reflected in many aspects of the everyday life of PWD including in law, education, livelihood and social participation. The disadvantages associated with each of these aspects are discussed in the following sections.

### **3.1.2. Issues and challenges in legal regulations and practices.**

Following the ratification of the CRPD in 2011, there have been attempts to propose new disability legislation, which is more consistent with the perspective of CRPD. In 2013, the Indonesian National Human Rights Commission submitted *Rancangan Undang-Undang tentang Penyandang Disabilitas* (Draft Law about People with Disabilities) to the Indonesian Parliament. This draft was intended to revise the previous legislation namely Law No. 4 of 1997, that had been consistently criticised for its disempowering approach to disability and therefore was inconsistent with the ratification of CRPD (Edwards, 2014; Nursyamsi, Arifianti, Aziz, Bilqish & Marutama, 2015). It was not until April 2016 that the draft was finally legalised and registered as Law No. 8 of 2016 on Persons with Disabilities (Mardjianto, 2016).

Compared to the previous law (i.e., Law No. 4 of 1997), Law No. 8 of 2016 represents a number of significant changes in how disability is defined and approached in legal regulations (Ratnaningsih, 2016). This new legislation represents a favourable shift toward a human rights perspective on disability. With this perspective, Law No. 8 of 2016 emphasises society’s obligation to act in accordance with the human rights of persons with disabilities

(Mardjianto, 2016; Ratnaningsih, 2016). In other words, this new law no longer views disability as a problem caused by individual pathology, rather “as a result of the failure of societies to be inclusive and to accommodate individual differences” (Pillay as cited in Edwards, 2014, p. 3). This change is reflected in the term used to refer to disability in this legislation. The term *cacat* (impaired or invalid) that was used in the previous law (i.e., Law No. 4 of 1997) is now substituted with *disabilitas* (disability).

Ratnaningsih (2016) argues that Law No. 8 of 2016 indicates a progressive shift in how the Indonesian government frames the issue of disability. However, since the law has just been enacted, it has not been followed by observable changes in the way disability is situated in Indonesian society. The everyday treatments of and attitude to PWD still strongly reflect the discriminatory views on disability, which was embodied within the previous law on disability (see for example Arisandhi, 2016; Kurniawan, 2016).

In the previous law which was entitled *Undang-Undang tentang Penyandang Cacat* (Law of Impairment Sufferer), disability was defined as a problem which results from physical and/or mental abnormalities that disturb, constraint or limit the individual’s capacity. By defining PWD as the ‘abnormal’ and ‘sufferer’, Law no. 4 of 1997 promoted the view of PWD as incapable individuals who need to be helped, rehabilitated or educated in order to fit with the ableism-driven society (Adioetomo, et al., 2014; Edwards, 2014). This view on disability has underpinned the exclusion, marginalisation and discrimination of PWD in many aspects of their life.

The reproduction of discriminatory views on disability have manifested in various other legal regulations and practices. One of the examples is Law No. 1 of 1974 about marriage regulation, which has not yet been revised. According to this law, polygamy and divorce are permitted when due to his or her disability, a spouse is not able to fulfil the obligation as a husband or wife (Edward, 2014; Syafi’ie, 2016). Another example is the

discriminatory practices in relation to the rights of PWD in accessing legal justice. Such discrimination was evident in Syafi'ie, Purwanti and Ali's (2014) study, which investigated the legal process of PWD who were sexually abused. They found that not getting accessible legal supports (e.g., the unavailability of support workers who have adequate sign language skill, dealing with prejudicial police officers, and working with a lawyer who did not have disability awareness) was a common experience among the participants of their study.

### **3.1.3. Issues and challenges in education systems and practices.**

Education is an area in which the disadvantages of PWD in Indonesia can be readily observed. In comparison to non-disabled people, the enrolment of PWD in formal education is significantly lower (WHO, 2011). According to the 2011 World Report on Disability, more than 80% of non-disabled children in Indonesia (6 – 11 years old) attended school while only 20% of children with disabilities from the same age group did so. Similar findings were reported for adolescences with disabilities (WHO, 2011).

The 2012 SNSAP-PWD provided a more detail description of the education profile of PWD in Indonesia (Adioetomo et al., 2014). As mentioned earlier, the 2012 SNSAP-PWD was a national survey targeted to identify the types of social assistance needed by PWD in Indonesia. In regard to the educational attainment, the survey found that not completing primary education was still a common experience among the respondents (Adioetomo et al., 2014). In addition, the survey provided a more detailed description of the situation by sorting the data using both low and high threshold of disability. Low-threshold of disability included the data from all respondents who have some difficulties, a lot of difficulty, or are unable to do an activity. In contrast, high threshold of disability only included data from respondents who experienced severe difficulty. When the data were sorted using high-threshold of disability, the percentage of the respondents who did not complete primary education was

significantly higher (Adioetomo et al., 2014). The following table provides a more detail description of these data.

Table 1. The Educational Attainment according to the 2012 SNSAP-PWD (Adioetomo et al., 2014)

Variable	Low Disability				High Disability			
Gender	Not finish primary	Primary	Secondary	Above Secondary	Not finish primary	Primary	Secondary	Above secondary
Male	19.7	31.09	45.60	4.15	41.69	29.67	26.73	1.92
Female	31.93	35.29	28.57	4.20	56.82	27.73	14.70	0.76
All	24.04	32.69	39.10	4.17	48.61	28.78	21.22	1.39

The data presented in the Table 1 above suggested that completing above secondary level of education was a rarity among the respondents. Furthermore, the survey indicated that in comparison to the male respondents, the percentage of the female respondents who did not finish primary school was higher either when the data were sorted using low or high threshold of disability. Such a finding illustrates how the disadvantage experienced by PWD in the area of formal education can be more complicated when combined with gender-based discrimination (Adioetomo et al., 2014).

This low participation in formal education reflects the ongoing structural, physical and attitudinal barriers experienced by PWD in Indonesia (Adioetomo et al., 2014; Afrianty, 2015; Irwanto et al., 2010; Tsaputra, 2014). The existing education system and infrastructures have not been able to optimally accommodate the participation of school age children and young people with disabilities (Adioetomo et al., 2014; Sunardi, Yusuf, Gunarhadi, Priyono & Yeager, 2011). For example, special schools in Indonesia have not been equitably distributed across urban and rural areas. Such schools are mainly located in urban areas and their capacity is much smaller than the numbers of school age children with disabilities.

Therefore, accessing special schools is often impossible for those who live in rural areas since it involves long distance travel to nearby cities, which can be quite costly (Adioetomo et al., 2014).

Responding to this kind of marginalisation, disability activists and organisations have been actively campaigning for inclusive education (Purbani, 2013; Tarsidi, 2004).

Responding to the campaign, in 2003, the Ministry of Education and Culture issued the Circular Letter No. 6719/C/I380/G.06/MN on inclusive education. This letter is an official call to regular schools to provide accessible education to children with minor disabilities (Adioetomo, et al., 2014; Irwanto, et al., 2010; Sunardi et al., 2011). Since then, there have been a number of regular schools in sub district levels appointed as the pilot projects of inclusive schools. However, the current situation indicates that the initiative on inclusive education has not been conscientiously implemented (Sunardi et al., 2011).

Some researchers argue that the current implementation of inclusive education tends to be inconsistent with the ideal of providing equal learning opportunities for all students (Adioetomo et al., 2014; Astuti, 2014; Sheehy & Budiyanto, 2015; Sunardi et al., 2011). These researchers identified that in many schools, which are appointed as inclusive schools, there have not been sufficient changes in their curriculum and teaching practices. The ideal of an inclusive learning process in which students with disability and non-disabled students learn together and have their individual needs and potentials optimally addressed is still rarely met (Sheehy & Budiyanto, 2015). What commonly happens is that students with disabilities are allowed to enrol in a regular school but they are separated from the regular learning process and community. They are assigned to special classrooms with special education teachers (Adioetomo et al., 2014; Astuti, 2014; Sunardi et al., 2011). Consequently, the existing practice of ‘inclusive school’ tends to reinforce the segregation between students with disabilities and non-disabled students.



The inadequate implementation of inclusive education is also reflected in higher education (Tsaputra, 2014). As suggested by the data presented in the Table 1 above, it is a rarity for PWD to enrol in tertiary education. Adioetomo et al. (2014) has identified that inaccessible education systems and practices are the key contributing factors in this enrolment gap. Among those contributing factors are disabling infrastructures (most campus buildings are not accessible), inaccessible registration and selection systems, and low disability awareness among administrative and academic staff (Adioetomo et al., 2014; Afrianty, 2015; Tsaputra, 2014)

Other than the absence of enforcement of the law, this discriminatory education system is rooted on the ongoing attitudinal barriers targeted to PWD (Tardi, 2011). Adioetomo et al. (2014) found that the inconsistency of schools in implementing the principles of inclusive education stems from the common assumption that children with disabilities do not have adequate learning capacity. Driven by the stigma associated with disability, teachers and school administrators are generally reluctant to accommodate students with disability. The enrolment of students with disabilities in regular schools is perceived as a threat to the school's academic credibility and prestige because providing inclusive education is associated with lower academic standards and achievements (Adioetomo et al., 2014).

#### **3.1.4. Issues and challenges in livelihood.**

Adioetomo et al. (2014) has outlined that opportunities for PWD to access formal education in Indonesia is very limited, and has also identified that this extends to difficulties in finding employment. According to the Ministry of Manpower and Transmigration Decree Number 205 of 1999, every workplace has an obligation to employ one person with disabilities in every 100 employees (*Kementrian Tenaga Kerja & Transmigrasi RI*, 2012). However, this regulation can be easily dismissed since there is another legal framework, which justifies a discriminatory act in industrial relations. According to Law No. 13 of 2003,

it is not illegal for a workplace to cancel recruitment or to terminate an employment if the candidate or the employee has become disabled (Adioetomo et al., 2014). Within such a context, therefore, a more viable option for PWD is to be self-employed. PWD with formal jobs are in the minority and they can usually expect that their disability will limit their possibility to have equal career promotion and workplace benefits compared to their non-disabled colleagues (Adioetomo, et al., 2014; Irwanto, et al., 2010).

Adioetomo et al. (2014) found that self-employment is the most common means of living for PWD in Indonesia as reflected in the 2012 SNSAP-PWD (Adioetomo et al., 2016). As presented in the Table 2 below, the survey found that majority of the respondents were self-employed. This finding is consistent when the data were sorted using both low and high threshold of disability. Either using low or high disability threshold, about 50% of the respondents were self-employed (Adioetomo, et al., 2014).

Table 2. The Type of Work according to the 2012 SNSAP-PWD (Adioetomo et al., 2014)

Disability Threshold	Self-Employed	Employer	Employee	Unpaid Family Worker
Low	63.13%	7.07%	21.72%	8.08%
High	49.67%	6.32%	33.33%	10.68%

Furthermore, Adioetomo et al. (2014) argued that self-employment becomes the most viable means of living for the majority of PWD in Indonesia because their limited opportunities to access non-formal courses or training that meet their talents and interests. The most common courses and training offered by government agencies or charity organisations are massage therapy, motorcycle repair, electronics, carpentry, and dressmaking. As observed by Adioetomo et al. (2016), underpinning such options is an assumption that the most suitable types of work for PWD are those which allow them to work by themselves. They identified that PWD are less likely to engage in training that would enable them to compete for a

professional role or position. As a consequence of being self-employed in fields that are not typically economically profitable, PWD often have to depend on charities or family support to survive financially (Salim & Syafi'ie, 2015). This situation also explains why PWD in Indonesia are 30% to 50 % more likely to live in poverty than non-disabled people (Adioetomo et al., 2014).

The absence of adequate social benefits or a social security system from the Indonesian Government has created a further challenge for PWD to earn a steady livelihood (JICA, 2015). A social security system has just been recently introduced in Indonesia (Aspinall, 2014; Sumarto & Bazzi, 2011; Widjaja, 2012). For decades, Indonesian people have had to rely on their individual resources to meet their basic needs including health, housing and education. It was not until 2011 that the Indonesian Government officially established what is called *Badan Penyelenggara Jaminan Sosial* or BPJS (National Social Security Provider Agency) as the national provider of universal health coverage and labour-related insurance (Aspinall, 2014; Widjaja, 2012). However, as reported by JICA (2015) these social benefits have not been equally available for every citizen throughout the archipelago. A lack of coordination among public institutions, inconsistent regulations and inaccurate demographic data are among the common reasons why the social security system in Indonesia has not been adequately implemented (JICA, 2015; Sunarto & Bazzi, 2011; Windarta, 2013; 2014).

In addition to the universal health coverage, the Indonesian Government provides social protection programmes targeted for PWD. One of them is the nation-wide cash transfer program for the vulnerable elderly and PWD, which is organised by the Indonesian Minister of Social Affairs (JICA, 2015). There are also province-based programs. For example, in Yogyakarta province (the province where the study was conducted), the Social Affairs Department provides *Jaminan Kesehatan Khusus Difabel* which is a health insurance

specifically targeted for PWD (Purnama, 2016). However, as with the national social security system, these social protection programmes have not been well implemented. Purwanto (2015, 2016) reported that inconsistent eligibility criteria have resulted in many PWD are unable to access any of these social protection programmes.

In conclusion, the implementation of social protection programmes in Indonesia is still unable to fully meet the needs of the disadvantaged groups in the country. For this reason, disadvantaged groups, including PWD, often have to rely on short-term or one-off assistance from charity organisations to be able to meet their basic needs (Salim & Syafi'ie, 2015).

### **3.1.5. Issues and challenges in social participation.**

Given that accessible public spaces and facilities are limited in Indonesia, opportunities for PWD to participate in social activities (e.g., religious, political and recreational activities) have been limited (Adioetomo et al., 2014). Formally, through Law No. 28 of 2002 on Building Establishments and Law No. 28 of 2009 on Traffic and Transportation, the Indonesian Government has obliged related sectors to put accessibility as a key principle (Irwanto et al., 2010). Nevertheless, in their case study in one of the big cities in Indonesia, Darmawan et al. (2014) found that the implementations of these regulations have not been significantly evident. Again, the SNSAP-PWD 2012 (a national survey on disability) provided a snapshot that illustrates the restrictions in social participation as reported by the PWD who became the respondents of this study (Adioetomo et al., 2014).

Table 3. Percentage of People Reporting Restrictions in Participation in Community Activities according to the SNSAP-PWD 2012 (Adioetomo et al., 2014)

Gender	Mild Disabilities				More Significant Disabilities			
	Community Organisations	Recreation, Sports, and Culture	Religious	Political	Community Organisations	Recreation, Sports, and Culture	Religious	Political
Men	12.00	17.86	3.56	11.76	62.94	60.26	46.91	53.38
Women	23.45	27.08	9.66	22.22	73.77	70.85	53.40	65.64

As presented in the Table 3 above, the respondents of the SNSAP-PWD 2012 reported restrictions in various aspects of community activities. In addition, the data above suggest that the percentage of the respondents who reported restrictions in their social life were generally higher among women and the respondents with more significant disabilities. Such a report confirms the importance of considering disability in its intersection with other discriminatory factors such as gender.

Several studies have suggested that inaccessible public spaces and facilities is not the only cause for restricted social participation among PWD in Indonesia. For example, in their study about disability in people affected by leprosy in Indonesia, Van Brakel et al. (2012) found that restricted social participation among the research participants was linked to the stigma associated with leprosy. The stigma could generate shame and discourage social participation, which might eventually increase the possibility of social isolation. Similarly, in his analysis on the political discrimination experienced by PWD in the Indonesian general election system, Salim (2014) found that an attitudinal barrier was one of the key causes. His analysis suggested that shame associated with disability led to many families not registering their family member who experiences disability as a voter. The discrimination was further institutionalised when the election committee failed to provide accessible infrastructure in every voting station. For example, ballot papers in Braille were not consistently provided in areas where there were voters who needed the accomodation.

Given that stigmatising views on disability still prevail, social isolation tends to be a common issue among PWD in Indonesia. This situation is reflected in a study by SIGAB, a local disability organisation in Yogyakarta, which documented the daily life of 10 PWD and their family (Salim & Syafi'ie, 2015). The study provided in-depth narratives of the everyday life of the study participants, particularly in relation to their struggles in dealing with the multiple barriers that they faced in their daily environments. Although not specifically

addressing the issue of social participation, some of the participants mentioned their experience of being excluded from community activities such as neighbourhood-based gatherings due to their disability. Their disability tended to be perceived as a personal weakness by the community that made them incapable to participate in the community activities (Yulianto, 2015).

### **3.1.6. Local disability organisations.**

The previous sections have outlined the challenging situations faced by PWD in Indonesia. According to Fuad (2011) and Yulianto (2011), it is such a situation that drives the emerging of local disability organisations, which aim to advocate the rights of PWD. In this section, I discuss the profile of local disability organisations in Indonesia and their contribution in advancing the public discourse on and responses to disability. Given that there is no official data on the number and profile of local disability organisations in Indonesia, I cannot provide an exhaustive coverage of the topic. Rather, the aim is to provide a general idea about the development and the role of local disability organisations in advancing disability movement in Indonesia.

The entry point for developing this section is the 31 local disability organisations which are listed in the website of *Persatuan Penyandang Disabilitas Indonesia* (Indonesian Association of People with Disability -- popularly abbreviated as PPDI). Based on this list, I conducted further Internet-based searching for each of these organisations. Only six of them have a well-developed and updated website. Information about the other organisations was also obtained via web search using the name of the organisation as the key word.

PPDI is the official, nation-wide organisation for PWD in Indonesia, which was established since 1987 ("Profil PPDI," n.d., para. 1). The original name of the organisation was *Persatuan Penyandang Cacat Indonesia* (Indonesian Association of Impaired Persons).

The name reflected the pathologising view on disability, which was previously the dominant perspective within government institutions. It was not until 2012 that the name is changed to PPDI (“PPCI berganti nama menjadi PPDI,” 2012, para. 1). The aim of the organisation is to advocate the full participation of and equalisation of opportunities for PWD in every aspect of life (“Profil PPDI,” n.d., para. 2). However, as a government-sponsored organisation, PPDI is often criticised for its tendency to represent the government’s agendas rather than advocating aspirations of PWD, which are not always in line with the contemporary government’s stated preferences (Fuad, 2011).

As an organisation that is fully funded by the government, PPDI has limited power to function independently (Fuad, 2011). With full support from the government, PPDI is the only organisation on disability, which has a chapter in each province and district of Indonesia. However, most of those chapters tend to operate based on top-down instructions from the related government institutions (Fuad, 2011). For example, during the fieldwork, some research participants mentioned government intervention in determining the selection of the coordinators for the PPDI chapters. It is for such a reason that not all PPDI chapters can function effectively as an umbrella organisation for all local disability organisations in each region (Fuad, 2011; Yulianto, 2011).

Among the types of local disability organisations in Indonesia are those which are established for a specific type of disability. As listed in the PPDI website, the examples for this kind of organisation are *Federasi Kesejahteraan Tuna Netra Indonesia* (Indonesian Federation for Blind), *Federasi Nasional Kesejahteraan Tuna Rungu Indonesia* (National Federation for Deaf Citizens) and *Ikatan Sindroma Down Indonesia* (Indonesian Association for Down Syndrome). In addition, there are local disability organisations, which are specifically targeted to accommodate particular professions such as the *Korps Cacat Veteran Republik Indonesia* (Indonesian National Corp of War Veterans with Disability) and

*Himpunan Pelaku Seni Diferensia Indonesia* (Indonesian Association of Artists with Disability) (“OPD Nasional,” n.d., para. 1)

Most of the organisations were initiated by PWD themselves and, generally, have been established since the early and mid of 1990s (Fuad, 2011). The central aims of the organisations are usually to improve the welfare of its members through social and capacity building activities such as providing scholarships and organising training for particular skills. For most of them, the funding comes from donations and international aid agencies. Some are well developed and able to maintain the sustainability of the organisation (Fuad, 2011).

One of the examples of self-initiated local disability organisations, which are quite successful in developing and maintaining the sustainability of the organisation, is *Mitra Netra*. *Mitra Netra* is a non-profit organisation that provides supporting facilities, training and scholarships for blind people, particularly those who are undertaking formal education (“Siapa itu Mitra Netra?” n.d., para 1 – 3). Among the *Mitra Netra*’s achievements is its initiative in producing audio books and establishing online Braille library (“Menghindari duplikasi,” n.d., para 1 – 5). However, my observation during the fieldwork process suggested that not all of the self-initiated local disability organisations are as progressive as *Mitra Netra*. Some of them end up as what is called *organisasi papan nama* (literally means a signboard organisation), an Indonesian idiom to illustrate organisations, which have an office and membership, but hardly have actual and continuing activities.

The self-initiated and specific local disability organisations as described above usually focus on initiating and developing support systems, which will enable their members to have better quality of life (Fuad, 2011). The issue of demanding structural changes that address unjust socio-political systems is less emphasised. It is here that the more recently developed local disability organisations are taking a leading role (Fuad, 2011; Yulianto, 2011). These organisations were generally established in the early 2000s as part of larger social changes in



Indonesia, which occurred following the major political reform of the nation in the end of 1990s. The shift toward a more democratic political atmosphere was taken as a momentum for advocating more critical approaches to disability (Fuad, 2011). Disability activists and academics have used the momentum to initiate a new model of disability organisations, which seek to advocate the equalisation of opportunities and social inclusion of PWD (Fuad, 2011, Yulianto, 2011).

Yulianto (2011) noted that this new model of DPO has gradually changed the public discourse on disability by advocating the view of disability as a socially constructed problem. The programs of these organisations are mainly targeted to change the unjust socio-political systems, which have normalised widespread disadvantages and discrimination. Furthermore, Yulianto (2011) explained that through activities like advocating research-informed disability policy, organising street demonstrations, proposing public hearing to key government institutions, and campaigning for progressive approaches to disability, such organisations have gradually raised public awareness on the political nature of disability issues (Yulianto, 2011). For example, the emergence these organisations has significantly contributed in popularising the term *difabel* and *disabilitas* (moving away from previous degrading terms), promoting the concept of inclusive schools, and advocating the legalisation of national and local regulations that are consistent with the ratification of CRPD (Fuad, 2011; Suharto et al., 2016; Yulianto, 2011).

Based on my observations, in Yogyakarta province (the province where the study was conducted), the examples for this new model of local disability organisations are *Sentra Advokasi Perempuan, Difabel dan Anak* (Advocacy Centre for Women, *Difabel* and Children) or abbreviated as SAPDA and *Sasana Integrasi dan Advokasi Difabel* (Integration and Advocacy Forum of *Difabel*) or abbreviated as SIGAB. The information presented in the website of these two organisations indicates that SAPDA and SIGAB have consistently

promoted more progressive approaches to disability since the early 2000s. For example, both SAPDA and SIGAB are actively advocating the new disability legalisation in provincial and district levels, pioneering the development of inclusive villages throughout Yogyakarta province, and monitoring, as well as tackling, discriminatory practices against PWD in areas such as health, education, public services and law (“Kerja Sigab,” 2013; “Profil Sapda,” 2016).

Compared to the government-sponsored disability organisations, like PPDI or organisations which are specific to a particular type of disability, Fuad (2011) and Yulianto (2011) argued that this new model of organisation has been more effective in transforming disability as a multi-sectoral issue. For instance, it is indicated by the ability of the organisation to invite the involvement of non-disabled people, who come from various backgrounds, including social activists, university students and academics (Fuad, 2011; Yulianto, 2011). However, as with most of the disability organisations, which are not funded by the government, these authors identify that this new model of disability organisations mostly relies on donations and international aid agencies to fund the programs. Consequently, like many other non-government sponsored disability organisations in Indonesia, maintaining the financial sustainability remains a challenging issue for the organisations (Fuad, 2011; Yulianto, 2011).

This limited review on the development of local disability organisations in Indonesia suggests that such organisations are an important driving force behind the gradual changes in how disability is constructed and addressed. This review also indicates that the development of such organisations in Indonesia cannot be separated from the broader historical, cultural and political context of their society. The definition of and approach to disability applied by these organisations are influenced by and respond to the historical, cultural and political forces that underpin how the society is organised. Drawing on this understanding, the next

section of this chapter examines the historical, political and cultural context in which the case for this study is situated.

### **3.2. The Socio-historical and Cultural Context of the Study**

The local disability organisation investigated in this study is FPDB, which is located in the Bantul district of Yogyakarta Province, Indonesia. In order to understand the significance of this organisation as an empowering setting, it is necessary for this study to take into account the broader historical, cultural and political contexts that shape the nature of community life in the villages where FPDB members live.

Administratively, Bantul District is part of Yogyakarta province, a province that is located in the centre of Java Island, Indonesia. Yogyakarta is renowned as the centre of Javanese culture. The majority of Yogyakarta's population, including those who reside in Bantul are native Javanese (Tickamyer & Kusujati, 2012). This cultural context underlines the need to situate the present study within the existing ideas and representations of Javanese culture (Zaumseil, Vacano, & Schwarz, 2014a). Such a discussion allows the study to better consider the personal, social and cultural significance of FPDB, particularly in terms of how this organisation is experienced as an empowering setting by its members (Aber et al., 2010; Maton & Salem, 1995).

In this section, I provide a general review on some of the key notions, which are commonly used to describe Javanese worldviews and how these influence the way people give meaning to their personal and communal experiences. I discuss these key notions in relation to the current socio-political factors, which shape contemporary Javanese rural communities. The more detailed descriptions about FPDB itself is presented in the following chapter.

### **3.2.1. Javanese worldviews as a personal framework.**

Characterising Javanese culture has always been challenging as it is reflected in much written ethnographic literature on Java (see for example Anderson, 1972, 1990; Berman, 1998; Geertz, 1960; Koentjaraningrat, 1989; Pemberton, 1994). Antlov and Hellman (2005) have argued that factors like pre-colonial monarchy, colonisation (the 16<sup>th</sup> to the mid of the 19<sup>th</sup> century), the awakening of Indonesian nationalism in 1945 and the authoritarianism of the New Order (mid 1960s to end of 1990s) are among the historical forces that cause Java to become a politically contested field of inquiry. Consequently, as much as these representations are portraying the experience of Javanese people, the images of Javanese culture often reflect the dominant powers that govern the society (Zaumseil et al., 2014a). For example, during the politically-repressive era of the New Order, being a Javanese was predominantly associated with the image of an individual who valued submissive attitudes and adherence to social hierarchy (Shiraishi, 1997). Whilst such an image may portray the general tendency among the Javanese, this representation also conceals the history of cultural and political resistance, which is a common practice among subordinate groups (Anderson, 1972, 1990; Antlov & Hellman, 2005; Guinness, 2009).

These historical contexts suggest that discussing Javanese culture and its characterisations need to be politically situated (Antlov & Hellman, 2005). As exemplified in the work of Antlov and Hellman (2005), Tickamyer and Kusujati (2012) and Zaumseil et al. (2014a), such historical contexts underline the challenge in defining Javanese culture due to its complexities, contradictions and paradoxes. Drawing on this understanding, I do not purport to provide an encompassing representation of Javanese worldviews and how these function as a personal framework. Rather, I selectively outline some key notions which are particularly relevant for this study whilst taking into account the historical and political embeddedness of those notions.

The extent to which Javanese worldviews are still perceived as an important personal and social reference is a subject of much debate (Widiastuti, 2009). Widiastuti (2009) further wrote that the physical and cultural landscape of people's everyday life has changed remarkably due to globalisation. As a result, there has been an increasing concern among the older generation that Javanese worldviews have gradually lost its significance. However, there are evidence that indicates the continuing relevance of Javanese worldviews in shaping the way people narrate their personal and communal experiences (Guinness, 2009; Hawkins, 1986; Newberry, 2007; Tickamyer & Kusujiati, 2012). Instead of losing its significance, Newberry (2007) pointed out that people's everyday practices often reflect the coexistence or hybridity of the Javanese tradition and the modern influences.

The belief of life as divinely predetermined is a part of Javanese worldviews, which has a continuing significance in the current context (Beatty, 1999; Zaumseil et al., 2014a). As explained by Guinness (1986) and Mulder (1996), underpinning this view is the Javanese cosmology, which assumes the existence of the Supreme Being that regulates the order of all existence (Guinness 1986; Mulder, 1996). This assumption is central to Javanese philosophy and theology, which is popularly known as *Kejawen*. As a belief system, *Kejawen* reflects the history of Java as a melting pot of religions and cultures. It is shaped by both the Javanese practices of animism and dynamism and later external influences such as Hinduism, Buddhism, and Sufi Islam (Beatty, 1999; Guinness, 1986; Mulder, 1996). As such, *Kejawen* is a key reference for explaining the Javanese ethics and code of conduct (Beatty, 1999).

In her analysis about the varieties of Javanese religion, Beatty (1999) noted that the existence of *Kejawen* can be traced back as early as the first century when Hindu influences reached the archipelago. Until the mid-1960s, it was common for the Javanese to identify *Kejawen* as their religion (Beatty, 1999; Tickamyer & Kusujiati, 2012). However, following the political tragedy in 1965 which resulted in the massacre of hundreds of thousands of

people who affiliated or were accused of having affiliation with the Communist Party, the Indonesian Government obliged every citizen to adopt one of the five formal religions acknowledged by the government (i.e., Islam, Buddha, Hindu, Protestant and Catholic). A refusal to do so would result in the accusation of being the supporter of communist ideology, thereby risking prosecution. Since then, the popularity of *Kejawen* as a formal religion has significantly diminished (Beatty, 1999; Tickamyar & Kusujiarti, 2012).

In the present time, the majority of native Javanese in Yogyakarta, (including those who reside in Bantul district) adopt one of the world's principal religions with Islam maintaining the largest proportion of followers (92% of Yogyakarta's population) and a minority of population follow Christianity, Hinduism and Buddhism (Badan Pusat Statistik DIY, 2015). Although *Kejawen* is no longer recognised as a formal religion, the worldviews and ethical values that are rooted in the *Kejawen* teachings have not entirely disappeared from people's everyday practices (Guinness, 2009; Tickamyar & Kusujiati, 2012). Tickamyar and Kusujiarti (2012) noted that people commonly merge the *Kejawen* teachings with the principles of their adopted religion, since they are often reinforcing similar worldviews and ethical values. One of them is the belief of life as the creation of the Supreme Being, which rules the cosmic order of human existence (Beatty, 1999; Guinness, 1986; Mulder, 1996).

In their analyses, Guinness (1986), Mulder (1996) and Zaumseil et al. (2014a) suggested that Javanese people's belief in the existence of the Supreme Being is generally accepted as a core approach to life. These authors further explained that this belief is manifested in the notion of *takdir*, which refers to the understanding that each individual is ascribed to certain roles or fate. Drawing on this understanding, Javanese people generally believe that the existential duty for every human being is to live one's life according to his or her roles and fate. For this reason, it is common for people to refer to deterministic or fatalistic views in giving meaning to their experiences or what happens in their environment

(Guinness, 1986; Mulder, 1996; Zaumseil et al., 2014a). Particularly in relation to the issue of disability, Thohari (2007) noted that the presence of such views explains why it is still common for people to look at disability as a personal fate. Disability is associated with notions like karma, wrath of God (*murka Allah*), divine test or punishment (*cobaan or hukuman*).

By believing that life is divinely predetermined, people are expected to have a more accepting (*nrimo*) approach to life by understanding that human have no ultimate control over their life (Guinness, 1986; Zaumseil et al., 2014a). Guinness (1986) and Mulder (1996) explained *Nrimo* as humbly accepting one's fate, without objection or protest. They further outlined that internalising the value of *nrimo* will enable people to have *sabar* (patience) (Guinness, 1986; Mulder, 1996). According to Berman (1998) *Sabar* refers to the absence of eagerness or headstrong passion; believing that everything has its own time and, therefore, cannot be forced or rushed. She explained that when people are *nrimo* and *sabar*, it will be easier for them to achieve the third ideal that is *ikhlas*. *Ikhlas* represents psychological resilience, which is acquired through detachment from the external world so that people are not easily disturbed when things are disappointing or go awry since they are aware that human has limited capacity to determine the course of life (Zaumseil et al., 2014a).

The internalisation of those three values (i.e, *nrimo*, *sabar* and *ikhlas*) is believed to be the prerequisite for achieving the state of *tentrem*, which is to some extent, represents the Javanese's idea of wellbeing (Guinness, 1986). As noted by Guinness (1986) and Mulder (1996), *tentrem* is a psycho-spiritual state, which is characterised with equanimity, composure and tranquillity of one's inner life (*batin*). Achieving the state of *tentrem* is idealised as a sign of a mature person as it makes people less likely to experience conflicts and tensions in their social relations that endanger both the person's inner calm and the social peace (Guinness, 1986; Mulder, 1996).

Studies on how people coped with the 2006 earthquake that caused 4,659 deaths in Yogyakarta (4,121 of them from Bantul District) suggest the ongoing relevance of these Javanese values as a personal and social reference in how people give meaning to their experiences. A number of studies (e.g., Imron & Hidayat, 2013; Kumara & Susetyo, 2008; Rakhman & Kuswardani, 2012; Yuniarti, 2009) reported how people used notions like wrath of God (*murka Allah*) and divine test or punishment (*cobaan or hukuman*) to narrate the disaster. In addition, these studies highlighted that people drew on notions like *nrimo*, *sabar* and *ikhlas* as the key determinants in developing their mental coping mechanisms to the physical and psychological burdens caused by the calamity.

The findings of these studies suggest the relevance of Javanese worldviews as both a personal framework and a social reference in how people give meaning to their experiences and environment. These studies indicate that referring to Javanese worldviews is essential to develop a better understanding on the attitude and behaviours of Javanese people. In addition, these studies also suggest the importance of considering Javanese culture as an overarching conception that underpins peoples' way of being. In this regard, the way people give meaning to their cultural identity as a Javanese seems to reflect the concept of primary communities as argued by Sonn and Fisher (1998). A primary community is "the one that provides the values, norms, stories, myths and a sense of historical continuity" (Sonn & Fisher, 1998, p. 461). In line with this understanding, the studies on how people coped with the 2006 earthquake as cited above indicate that being a Javanese is a primary identity that provides people with cultural knowledge and systems of meaning. This concept may explain why *Kejawen* teachings still become an important point of reference for Javanese people, despite their adoption of modern religions.

In studies about people's responses to the earthquake, the values of *nrimo*, *sabar* and *ikhlas* are often discussed as part of the Javanese local wisdoms, which contribute positively



to the people's resilience (e.g., Kumara & Susetyo, 2008; Zaumseil, von Vacano, Schwarz, Sullivan, & Prawitasari-Hadiyono, 2014b). However, as argued by Antlov and Hellman (2005), the interpretation of these values needs to take into account their historical and political embeddedness. They suggest the importance of considering factors like political power and social class in understanding the meanings of these values in people's everyday lives.

Whilst the values of *nrimo*, *sabar* and *iklhas* are often portrayed as the common virtue among the Javanese, Antlov and Hellman (2005) suggested that a political analysis on these values may produce a different story. For example, in his study about a local Non-Government Organisation (NGO), which worked with families from Yogyakarta's slum areas, Guinness (2009) found how such values were used by the ruling elites to demand unquestioned obedience from the marginalised groups in order for the elites to maintain their privileges. This study illustrates how the values of *nrimo*, *sabar* and *iklhas* were portrayed as the expected virtues of *wong cilik* (the low class, the have-nots) but not as much from *penggede* (the elites, the haves). It is a common practice that *wong cilik* who are outspoken in expressing their opinions or aspirations will be socially sanctioned by being labelled as not having *nrimo* attitude (Guinness, 2009).

The illustration above suggests that these values of *nrimo*, *sabar* and *iklhas* do not merely represent what is called 'the local wisdom'. Rather, they also reflect the political subordination within this cultural context. Therefore, in the Javanese context, working with the marginalised groups toward an empowering situation often involves the process of deconstructing these attitudes of subordination since they can be deeply internalised among the people (Guinness, 2009). As exemplified by the local NGO in Guinness's study, an important aspect of their works with the targeted families was to recognise the internalisation

of these attitudes of subordination and producing alternative narratives to counter the outside forces that reproduce and enforce the subordination.

### **3.2.2. Community life in rural areas.**

The previous section outlines some aspects of Javanese worldviews and how these function as a personal framework. In this section, I shift into the social aspects of rural community life in the Javanese cultural context. Beard and Dasgupta (2005) argued that defining rural community in the Javanese context is becoming more challenging as industrialisation has gradually changed the physical and social landscape of the island with urban and rural areas increasingly merge. Considering such a change, therefore, in defining the term ‘rural’ I mainly refer to the geographical context of the villages, which are located outside of the city centre, and the presence of agricultural areas as the spatial, economic and cultural markers of the villages (Tickamyer & Kusujiati, 2012).

The villages where FPDB members live are located about 25 kilometres outside the Yogyakarta’s city centre. However, with the current infrastructure development (e.g., the asphaltting of connecting roads between villages), the distance between these villages and Yogyakarta’s city centre may no longer create the same sense of isolation. With the expansion of global economy market, there are increasing similarities between the daily life in the villages and in the urban areas due to factors such as widespread access to internet, affordable smart phones, and private ownership of cheap motorcycles (Widastuti, 2009).

Despite the increasing similarities, there are still some factors that differentiate community life in villages and urban neighbourhoods. As noted by Tickamyer and Kusujiarti, (2012), the inhabitants of Javanese villages are generally more ethnically homogeneous and have deep roots in their communities compared to those who reside in urban areas. Villages in Yogyakarta typically evolve from groups of extended families. The history of villages as a

community with shared familial roots is continuously reasserted in various social rituals for example through the tradition of having communal feasts (Guinness, 1986; Newberry, 2007). In addition, with agriculture activities still present in the community, there are some collective activities, which are specifically related to farming practices. For example, in one of the villages in which I did my fieldwork, there is an annual ritual called *Merti Deso* (literally means nurturing the village). *Merti Deso* is an annual village festival in which the villagers celebrate the harvest time and perform some collective rituals, which are intended to show their gratitude and respects to the Mother Nature (Endraswara, 2006).

It is this historical context of villages as the extension of people's primordial network that holds the social and cultural significance of community life in rural areas (Tickamyer & Kusujiati, 2012). Despite the argument about the loss of villages' organic solidarity due to the increasing individualisation, Newberry (2007) found that many aspects of community life in rural areas still reflect the idea of a village as a network of communal exchange and cooperation. The forms and manifestations of this emphasis on communal connectedness have changed over time as these are influenced by the broader economic and political context. However, there are still the same patterns of social interdependence (Guinness, 2009).

During the New Order era, the Indonesian Government obliged every local community to have certain types of regular community gatherings or activities as a way to exert their controlling power. Instead of merely functioning the gathering or activity as a manifestation of their forced political obedience, Guinness (2009) and Newberry (2007) observed that villagers often used the gathering or activity as a vehicle for maintaining the tradition of communal exchange and cooperation between them (Guinness, 2009; Newberry, 2007). For example, one of the mandatory community activities during the New Order era was the *Program Kesejahteraan Keluarga* (Family Welfare Program), a village based organisation for women. The organisation was intended as a social forum, which employed

women as voluntary workers to undertake and disseminate the developmental programs of the government. However, as documented by Martin (2004), in most villages, the program was mainly used as a rotating credit group among women, which provided an exchange of financial assistance between families.

The fall of the New Order regime has brought changes in the nature of community life in general. The mandatory community activities installed by the New Order have not been completely abandoned, but there is less emphasis for people to function the activities mainly as a forum for disseminating the agendas of the government (Martin, 2004). Rather, people maintain the activities as a social space to manage and reassert the significance of mutual exchange and cooperation in their community life. It is through such social forums that people informally organise the exchange of information, goods and services between households (Guinness, 2009; Martin, 2004).

The mutual exchanges as described above are not only limited to tangible resources, but are also extended to psychosocial supports (Guinness, 1986, 2009; Newberry, 2007). For example, it is reflected in how people give meaning to their participation in collective religious activities in the community. As discussed in the previous section, religiosity is strongly emphasised in people's everyday life. During my fieldwork, I found that collective religious gatherings tend to be highly popular among the villagers. Generally, each family will take turn to host a collective prayer or deliberately organise it so that neighbours would come to provide blessings and prayer for the family's particular intention, such as wedding or a birth of a child. As noted by Guinness (1986; 2009) and Newberry (2007), participating in such an activity is not only about manifesting people's religious belief and identity, but also as a way to signify an investment in the network of mutual exchanges and cooperation that define their community life. This kind of communal practice provides another illustration of

how Javanese culture has become an overarching framework that orients the way people enact their religious belief.

With its emphasis on the value of communal solidarity, community life in rural Java has often been romantically portrayed as a harmonious, homogenous, non-confrontational and collective-oriented social territory (Antlov & Hellman, 2005). Such a depiction is generally encapsulated within the notion of *rukun* (social harmony) and *gotong royong* (mutual solidarity/cooperation). The two notions are often referred as the key features of Javanese local wisdom (Zaumseil et al., 2014b). To some extent, such a depiction may represent the actual situation of community life in rural Java. However, by taking into account the broader socio-political context, this emphasis on social harmony and mutual solidarity may generate a different explanation (Antlov & Hellman, 2005; Guinness, 2009).

Guinness (2009) and Newberry (2007) observed that within the historical and political context of Indonesia, the emphasis on social harmony and mutual solidarity may also represent the collective strategy of the people to deal with the absence of adequate public services. My observation during the fieldwork suggested that in the Indonesian context, where public service is typically framed as the state's generosity rather than responsibility, having poor public services have been perceived as normality by most Indonesians. Therefore, people often have to rely on their own resources and efforts to meet their basic needs such as in health and education. In this kind of condition, Guinness (2009) argued that mutual solidarity serves as important social resources and insurance. For example, during my fieldwork I found that borrowing a neighbour's car was a response to the absence of reliable ambulance service. Likewise, participating in a village rotating credit group was a helpful resource for low income families due to the unreliable social benefits provided by the government.

Both the historical context of rural communities as a kinship-based community and the broader political factors as described above explains the significance meanings of being

socially connected. This situation suggests the cultural and economic pressure that encourages people to maintain their involvement in the network of communal exchange and cooperation (Guinness, 2009; Newberry, 2007). Participating in community activities and rituals is one of the ways through which people maintain and strengthen their involvement. Through such an involvement, people implicitly declare their willingness to be a resource for the others, as well as making investment for their future needs when they require the assistance of others (Guinness, 2009; Newberry, 2007).

Salim and Syafi'ie (2015) identified that for PWD, this kind of socio-cultural context poses both protective and risk factors. As established in the previous section, disability has not been systematically and structurally addressed, therefore, PWD in Indonesia are generally facing greater challenges in their everyday life compared to non-disabled people. In such a context, living in a community that emphasises mutual exchange can serve as a protective factor. For example, during my fieldwork, I found that familial connections could create access to employment, which otherwise might not be available due to the discriminatory employment environment in Indonesia. However, I observed that such a socio-cultural context could put more stress on the social isolation of PWD and reinforce the pitying views on disability. As documented by Salim and Syafi'ie (2015), with people are generally expected to involve in community activities and rituals, the inability of PWD to participate (due to the cultural and environmental barriers) may strengthen their experience of social isolation.

### **3.2.3. Villages as an administrative unit.**

The history of Javanese villages as a kinship-based community is not the only factor that shapes the texture of rural community life in Java (Tickamyer & Kusujiati, 2012). The dynamics of village community life is also a product of the interventions and policies of the

ruling governments since the colonial period up until now in what is called the reformation era (Guinness, 1986, 2009). This section provides a more detail description on the political context of Javanese villages as an administrative unit. Such a description is relevant to understand the significance of FPDB as a social space where PWD can exercise their political agency.

*Desa* (village) is the lowest level of government in the Indonesian political structure, which is headed by a *Lurah* (*village head*). *Desa* usually consists of a series of *pedukuhan* (sub-villages) and is led by a *Dukuh* (sub-village head). Both *Lurah* and *Dukuh* are directly elected by the villagers (Tickamyer & Kusujiarti, 2012). According to the 2015 Bantul Population Report, the number of sub-villages in each village in Bantul District ranged from two to 24 depending on the size of the area. The number of population in each village was reported approximately 3,000 to 54,000 people (BPS Kabupaten Bantul, 2015).

Historically, the administrative structure of Javanese villages was created by the colonial government as an instrument of control (Guinness, 1986). The Indonesian government then adopted such a function. Particularly, during the New Order regime (1966 – 1998), village administrative structures were strongly enforced as a tool for exerting the ruling government's political control (Guinness, 1986, 1994).

The New Order regime arose to power following a political upheaval in 1965 that resulted in the massacres of hundreds of thousands people associated or were accused of having association with the Communist Party or other leftist organisations. This is not to mention were another 100,000 or more people who were imprisoned without any prosecution (Mulder, 1996). Anderson (as cited in Li, 2007) described that this tragedy severely tormented Javanese local communities, not only because of its massive violence, but also because it made fellow villagers suspicious of each other. Systemic political propaganda provoked

villagers to treat other villagers who were linked with any leftist organisation as “animals or devils, appropriate subjects for sadistic torture and murder” (p. 53)

Since then, Indonesia in general was under strong political surveillance. The government decided on uniformed types of community organisation and activities in every local community. Such practices gradually diminished most of locally initiated community organisations and activities. These organisations were replaced by government-sponsored associations of which the main function was to relay the government political propaganda. It was the time when the term *partisipasi masyarakat* (community participation) was mainly associated with local communities’ compliance in supporting the government’s development programs (Guinness, 1986, 1989, 1994, 2009; Li, 2007; Mulder, 1996)

Under this political atmosphere, most local leaders functioned more as the government’s agent rather than as the representation of the community (Bebbington, Dharmawan, Fahmi & Guggenheim, 2006). Therefore, this saying was and still very popular in Indonesia to illustrate the top-down atmosphere of local communities: “allow the villagers a role, but give the village head the final word, and just to make sure, give the district head the right to veto everything” (Evers as cited in Bebbington, 2006, p. 1961). With the political trauma of the 1965’s tragedy and the systemic depoliticisation applied by the New Order regime, political participation has become a distanced idea for most local people in Indonesia. The idea of being politically active or articulate generally evokes either fear or apathy (Hadiwinata, 2004).

Since the coming of the Reformation Era in the end of 1990s, there has been a gradual shift toward a more democratic political discourse both nationally and locally (Bebbington et al., 2004; Colongon, 2003). However, the scepticism and apathy of villagers have not been easily diminished. Moreover, the old practices of top-down leadership have not been completely abandoned. It is still common to find village head and officers acting more like



state bureaucrats rather than as public servants for the people. Bebbington et al. (2004) found that patron-client relationship still features significantly in village politics. It is, therefore, although the current political systems provide more opportunities for villagers to have direct participation in decision-making processes, people are generally still reluctant to be involved.

The socio-cultural and political context of rural community life as described above became the setting where FPDB is situated. To a large extent, the meanings and significance of this organisation (as presented in chapter 7 and 8) reflect the participants' responses to such a historical, cultural and political context.

### **3.3. Chapter Summary**

In this chapter, I describe the broader historical, cultural and political context that influences how disability is situated in the Indonesian context. Particularly, I highlight the gap between the state's legal recognitions of the rights of PWD and their actual living condition, which are mainly characterised by pervasive marginalisation and discrimination. The prevailing personal and medical perspectives toward disability have created multiple barriers, which greatly challenge the everyday life of PWD in various areas including law, health, education, livelihood and social participation.

In addition, I also examine some key features of Javanese culture, which provide a relevant reference in understanding how disability has been generally approached in the particular local community where FPDB is located. The review on Javanese culture is also intended to describe the nature of rural community life in the villages where the members of FPDB live. This review introduces some cultural and political issues specific to this locality, which is relevant to understand the meanings of participating in a local disability organisation. A more detailed description about FPDB is presented in the next chapter.

## Chapter 4

### *Forum Peduli Difabel Bantul*

This chapter describes *Forum Peduli Difabel Bantul* (FPDB), a local disability organisation in the Bantul District of Yogyakarta Province, which has become the site of this current study. As an organisation FPDB was established as part of a community based rehabilitation (CBR) program that was initiated by a local NGO, *Karitas Indonesia Keuskupan Agung Semarang* popularly known as KARINAKAS. In May 2006, a massive earthquake hit Bantul and resulted in thousands of death and injury (Effendi, Manning, Hunt & Suharman, 2016). KARINAKAS initiated the CBR program as a response to the increasing numbers of people living with disability (PWD) due to injury sustained in the earthquake. As part of this CBR program, KARINAKAS facilitated the development of FPDB, which was intended to be an advocacy group for PWD in this district. Considering such a background, therefore, the description of this organisation needs to be discussed in relation to the socio-political context of Bantul district in the post-disaster situation, particularly in relation to the implementation of the CBR program.

In the first section of this chapter, I describe the socio-economic implications of the 2006 earthquake, which provides a particular background for understanding the dynamics of FPDB as a disability organisation. Then, I outline the CBR program and its implementation. This section specifically outlines how the CBR program had functioned as the catalyst for the development of FPDB. Last, I describe the profile of FPDB, which includes a detailed account of its history and current development. The information presented in this chapter is largely drawn from the interviews and observation that I conducted during my fieldwork (October 2014 – February 2015).

#### 4.1. The 2006 Earthquake and its Socio-economic Implications

Bantul District is located in the southern part of Yogyakarta province. With a total area of 506.85 Km<sup>2</sup>, Bantul comprises approximately 15% of the total area of this province (Kusumasari & Alam, 2012). According to the 2015 Bantul Population Report, the estimated total population was 968.632 people, distributed across 75 villages. The population density was approximately 1.991 persons per square kilometre (BPS Bantul, 2015). Villages that are closer to the Yogyakarta's city centre (the north side of Bantul district) tend to have a higher population density due to the expansion of housing areas in this side of the district. On the southern end of the district (which is bordered by the Indian Ocean) are villages with lower density and wider agriculture area. Most of FPDB members live in villages that are closer to the southern end of the district.

Economically, other than from its agriculture production, Bantul is well known as the centre of various industries (e.g., wooden crafts, ceramics, teak furniture, *batik* [traditional cloth] and food production) that range from home-scale businesses to middle size manufacturing (Joakim, 2013; Kusumasari & Alam, 2012). My observation during fieldwork suggested that the presence of such industries provides an important means of living for low-income families (i.e., those who do not have the human capital to work in 'white collar' jobs). Their livelihood usually comprises a combination of farming activities and working in such industries either by being a labourer or running their own home-based micro business.

As noted Zaumseil et al. (2014a), working as a farmer or a factory labourer barely provides sufficient and regular income for low-income families in this district. My observation suggested that the income is generally sufficient for paying daily expenses (e.g., meal, transport), but little can be saved for costs related to health, housing, education and unforeseen hardship. Combined with the inability of the Indonesian Government to provide an adequate social security system, low-income families often have to rely on their informal

networks (e.g., loan from extended families or neighbours) to be able to survive financially (Joakim, 2013; Zaumseil et al., 2014a). Consequently, when a massive earthquake hit the area in 2006, the socio-economic impacts of the disaster were severe, especially for those from low socio-economic groups (BAPPENAS, 2006).

In May 27, 2006 a 6.2 magnitude earthquake hit Yogyakarta province with Bantul suffering the worst impact as the epicentre of the earthquake was in the Bantul coastal area (Effendi et al., 2016). Table 4 outlines the detail of the damages caused by the earthquake.

Table 4. Estimated Damages of the 2006 Earthquake in Bantul District (BAPPENAS, 2006)

	Estimated Damage and Losses
Human	4,121 deaths; 12,026 injuries
Housing	43,753 house destroyed; 33,137 damaged
Education	949 school buildings destroyed
Health	Causing the damage of public health facilities which was equal to 418,380 billion Indonesian Rupiah
Business	Affected three quarters of enterprises in the district (14,600 out of 21,300 medium to small scale business units)
Employment	The loss of 5,957 jobs

With such a massive extent of devastation, the 2006 earthquake has created multi-dimensional challenges that impact upon the communities far beyond the emergency relief stage (BAPPENAS, 2006). One of these challenges is the increase in the number of people who have become permanently disabled due to injuries sustained in the disaster. In total, the earthquake caused 1,449 people to become disabled (“The Dream of Inclusion for All”, n.d.). According to Fauzia and Sholihah (2014), there were estimated 500 people who received spinal cord injury, with 350 of them acquiring paraplegia. This situation has driven the

initiation of several CBR programs, including the one that was initiated by KARINAKAS, which then led to the development of FPDB.

In the following section, I describe how this post-disaster context has complicated the socio-economic challenges experienced by PWD in Bantul District. In addition, I also outline the emergence of CBR programs as a response to such a situation, particularly the one initiated by KARINAKAS.

#### **4.2. Post-disaster Context, Disability Issues and the Emergence of CBR Programs**

The increasing number of people who had become disabled has brought challenging consequences, not only to the individuals who experienced the injury, but also to their families (Suharto, 2011). For example, some families had to deal with greater financial challenges, as they had to cover long-term medical treatments for the injured family member. As noted by Zaumseil et al. (2014a), some families had to sell their productive assets or used any reserves to cover expenses related to the post-emergency situations such as medical bills, reconstruction costs and rebuilding their home-based micro businesses.

Some families experienced more complicated socio-economic challenges because the family member who had become disabled was the main income earner. Suharto (2011), in his qualitative study on a number of families affected by the earthquake, found that having disability or long-term injury had frequently hampered the survivors to return to their jobs such as being a farmer, a labourer or running their own home-based micro enterprise. In such a situation, the other adult in the family was compelled to take the role as the main income earner for the family. Such a shift could be challenging because finding employment was generally difficult after the earthquake (Suharto, 2011).

According to the Indonesian Government National Development Planning Agency, the earthquake affected 9,588 formal businesses and 5,040 informal sectors in Bantul District.

This resulted in the loss of 5,957 jobs and the increasing unemployment (BAPPENAS, 2006). This crisis did not only bring economic impacts, but also psychological and social challenges for such families. Further to this hardship, dealing with resulting personal identity crises and facing a discriminative social environment was among the many psychological and social implications that might challenge many families in the district (Suharto, 2011).

Such a situation had raised awareness about the need to approach the disability issue from a broader socio-cultural perspective and not relying solely on medical interventions targeted at the affected individuals (KARINAKAS Program Manager, personal communication, January 2015). It was this awareness, which then led to the emergence of CBR programs in some villages, initiated either by government or non-government organisations. How each of these organisations implemented their CBR programs were varied. Some were more oriented toward the social model of disability, but there are also some CBR programs that still operate with a medical model of disability (Suharto, 2011)

The concept of CBR was originally developed by WHO in the 1970s. At that time, CBR programs were generally considered as a cost-effective strategy to make rehabilitation services available to PWD, particularly those who live in rural areas of low-income countries. As a concept, CBR was intended to address the limitations of institutional-based rehabilitations, because such rehabilitations tended to require high investment in physical infrastructures and the coverage were limited (WHO, 2010).

In its early practices in the 1970s, CBR programs tended to be heavily influenced by the medical model of disability. The term ‘rehabilitation’ was mainly associated with the practices of rehabilitating the physical impairments of PWD through activities such as physiotherapy and providing assistive devices (Barnes & Mercer, 2003; WHO, 2010). Little attention was paid to address the socio-economic and political aspects of disability. The term ‘community’ mainly referred to the practices of training community members (usually non-

disabled community members) to be able to provide rehabilitative services (e.g., physiotherapy) or to make appropriate referral options for PWD in their local communities (Barnes & Mercer, 2003; WHO, 2010). In this sense, the early models of CBR tended to offer the same kind of interventions, which generally characterised institutional-based rehabilitation, but the interventions were delivered in community settings instead of in hospitals or rehabilitation centers.

With the rise of disability movement, the early models of CBR was often criticised for its pathologising and colonising approach (Barnes & Mercer, 2003; Suharto, 2011). For instance, the early projects of CBR was criticised for its tendency to reinforce the dependency narrative of disability by positioning PWD as passive objects of intervention. In addition, such projects were often criticised for its lack of sensitivity to local culture and practices as the design and implementation of the programs were predominantly delivered in Western fashion (Barnes & Mercer, 2003; Suharto, 2011).

In response to such criticism, there have been some important changes in the recent models of CBR. Current practices of CBR are generally more oriented toward the social model of disability, with more emphasis are placed on rehabilitating the discriminatory social structure (Barnes & Mercer, 2003; Suharto, 2011; WHO, 2010). Within this new model of CBR, the term community is generally associated with the attempts to frame disability as a social issue, which requires the involvement of the community as a whole to address the marginalisation and discrimination experienced by PWD. Instead of being positioned as passive objects of intervention, PWD are considered as the leading actors who should be actively involved in designing and implementing CBR programs (Barnes & Mercer, 2003; Suharto, 2011; WHO, 2010).

This new model of CBR had become the main framework for several organisations, which initiated the CBR programs in Bantul. In these organisations, the CBR programs were

more oriented toward community development practices and the promotion of equal rights rather than on medical rehabilitation. KARINAKAS was one of such organisations. Drawing on the social model of disability, KARINAKAS set up the CBR program as a strategy that can “integrate the community’s participation and the government’s support as well as considers diffabled people’s voices during the implementation” (Suharto, 2011, p. 30). As a result, KARINAKAS has made concerted efforts to ensure the active participation of PWD in the implementation of the program. Facilitating the development of FPDB was one of such efforts.

My observations during the fieldwork suggested that approaching disability as a social issue, like that practised by KARINAKAS, was still a rarity in Indonesia. As reported by some scholars (e.g., Adieotemo et al., 2014; Suharto, 2011; 2016), I found that disability had been predominantly framed as an individual-medical issue that positioned PWD as passive objects of intervention. For instance, such a tendency was strongly reflected in how the local government responded to the increasing numbers of PWD as a consequence of the earthquake.

In response to the increasing numbers of PWD, the local government built a rehabilitation centre in Bantul District. As written in its vision and mission statements, the aim of the center is to “help PWD acquire their self confidence and self esteem by developing their capacities, so that PWD are able to be independent and fulfil their social roles in their family and community” (BRTPD brochure, p. 2, n.d.). This statement implicitly assumes that the problems with disability are located within the PWD themselves (i.e., having low self confidence and self esteem). In this sense, PWD are considered as the rehabilitation target, while the societal factors that have contributed to their marginalisation and discrimination remain unquestioned.



Before FPDB was officially established, some of its members came to know each other through their involvement in this center. While acknowledging the practical benefits that they got from attending the vocational training programs held in the center, some of them expressed their disappointment with how the center was operated. They mentioned that the vocational training programs offered at the centre (e.g., computer training, dressmaking and massage therapy) did meet their interest and talents. However, they were disappointed by what they perceived as a patronising approach used by the staff of the center to deliver the programs. For instance, they criticised the fact that none of the trainers employed in the center was a PWD, while there is a number of PWD in Bantul District who have relevant capacities to be involved as part of the trainer team. According to one FPDB members, currently, there are only two PWD employed in the center, but in a menial position as the office cleaners.

It was such a disappointment, which then planted the seed for the development of FPDB as a disability organisation. The disappointing experience with the center had encouraged the early members of FPDB to initiate a disability organisation, which would genuinely advocate their struggle for justice and equality. In this sense, the birth of FPDB as an organisation was partly driven by the frustration shared among the early members of FPDB due to the subjugating practises commonly targeted toward PWD, such as the patronising experience that they had at the rehabilitation center.

Although the early members of FPDB had become known to each other since 2006 (after the earthquake), it was not until they met with KARINAKAS in 2009 that FPDB was officially established. In the next section, I describe the CBR program that was initiated by KARINAKAS and how the program led to the establishment of FPDB.

#### **4.3. The CBR Program by KARINAKAS and the Development of FPDB**

The involvement of KARINAKAS in the local communities in Bantul District was started when it was one of the humanitarian agencies that provided emergency and relief

assistances in the aftermath of the earthquake. KARINAKAS continued its services in the post-emergency phase by providing on-going medical services for the survivors who had long-term injuries (KARINAKAS program manager, personal communication, January 2015). Such services were crucial because at that time the local government had limited capacities to provide the required medical services due to the severe damage of the public health facilities (Effendi et al., 2016; Joakim, 2013). KARINAKAS continued their involvement in the recovery phase by assisting the affected families with free medical services such as physiotherapy and daily care (Suharto, 2011). KARINAKAS staff also trained the family members of the injured survivors to provide the required daily activity assistance such as transferring from the bed to wheelchair, moving to the toilet and to do a series of physical exercises (KARINAKAS Field Officer, personal communication, January 2015).

It was from the interactions with these affected families that KARINAKAS recognised the complexities of the socio-economic challenges that were faced by survivors. Furthermore, such interactions had developed an understanding about the limitations of individual-based medical interventions in addressing the challenges (KARINAKAS Program Manager, personal communication, January 2015). The magnitude and complexity of the problems had raised awareness about the need to initiate a community-based intervention that promoted the equalisation of opportunities and social inclusion of PWD in the area. Driven by such awareness, KARINAKAS eventually started a CBR program, which was implemented in five villages in Bantul district, from 2007 to 2015 (KARINAKAS Program Manager, personal communication, January 2015).

The overall aim of the CBR program was to promote equalisation of opportunities and social inclusion of PWD in every aspect of their personal and social life (KARINAKAS Unit Manager, personal communication, October 2014). Informed by the WHO - CBR Matrix

(WHO, 2010), the program comprises five key components, including: (a) promoting accessible health systems and services; (b) promoting inclusive education systems and practices; (c) promoting sustainable livelihoods for PWD and their family; (d) promoting the social participation of PWD; and (e) enhancing cooperation between related local actors (i.e., PWD and their families; organisations and communities; and the relevant governmental institutions) in advocating the rights of PWD in all aspect of development (KARINAKAS Unit Manager, personal communication, October 2014).

As indicated by these five components of the program, the implementation of the program required multisectoral cooperation as well as active involvement of the key local actors. As the initiator of the program, KARINAKAS aimed to mainly function as a facilitating partner for the local community. The key local actors, particularly PWD, their families and the village government, were expected to gradually take the ownership and leadership of the program (KARINAKAS Unit Manager, personal communication, October 2014).

In order to encourage the active involvement of PWD, KARINAKAS initiated some activities, which were intended to connect PWD in the participating villages, such as by organising social gatherings and training programs for PWD. Through such activities, KARINAKAS aimed to facilitate the development of a local disability organisation, which would function as an advocacy group for PWD in the area. When KARINAKAS initiated the CBR program in 2007, there had only been a few disability organisations in Bantul District, which were mainly government-sponsored disability organisations and organisations for a specific type of disability. However, these existing disability organisations had not been able to function effectively as advocacy groups as these organisations rarely had actual and continuing activities. In addition, the existing organisations were often perceived as being less inclusive for the organisations only accommodated PWD with a specific type of disability or

because the organisation tended to be operated in a top-down approach (KARINAKAS Program Manager, personal communication, January 2015).

The attempts of KARINAKAS to support the development of local disability organisation eventually found its momentum when KARINAKAS staff met with the early members of FPDB. In the next section, I discuss how this meeting led to the establishment of FPDB as a disability organisation.

#### **4.4. *Forum Peduli Difabel Bantul* (FPDB): The beginning and its current development**

As a disability organisation, FPDB was officially established in 2009. However, as an informal gathering forum, this organisation has been started since 2006, a few months after the May 2006 earthquake. It was started from the interactions between a number of PWD in Bantul district who occasionally met in the town square (i.e., an open lawn square about the size of a football stadium which is located in the front of the office of the district head). Gathering in the town square is a popular early evening social activity among those who live nearby the centre of Bantul district. Every early evening, the area is always busy with people gathering around many food vendors or simply just to watch various groups playing soccer in the middle of the square. Agus and Ilham (pseudonym) are the initiators of FPDB who tend to spend their early evening by hanging out in the town square. It was from this casual interaction that FPDB as an informal gathering forum was initiated.

Agus has been living with disability since he was child, while Ilham becomes disabled because of the earthquake. Both are in their mid-thirties. Since years before the earthquake, Agus was involved in various disability organisations, including having several years of working experience in a privately owned rehabilitation centre in which he worked as a computer instructor. Through these experiences, Agus developed his networks with progressive disability activists as well as his understanding of disability theories, including

the social model of disability. He described himself as ‘a critical person’ in reference to his frequent involvement in collective actions, which were targeted to criticise the discriminative system and practices against PWD in the society.

It was through their occasional meetings in the town square that Agus started to have discussions with Ilham about disability issues. Ilham himself is an artist (painter and musician) with extensive network of friends. Through his network, Ilham started to invite other friends with disabilities to join him and Agus to hang out in the town square while having a chat about disability issues. Gradually, the number of PWD who came to hang out in the town square was increasing. There were 8 to 10 persons joining the group whenever they were hanging out in the town square. The people who joined the ‘crowd’ were particularly those who were interested in the critical views on disability that were passionately shared by Agus. He mentioned that criticising the subjugating approaches commonly used by key government agencies in addressing disability issues was a recurrent conversation topic. The conversation also brought up their disappointment on the existing disability organisations in the district, which in their perception appeared to be elitist and operated in a top-down approach.

This shared concern and interest eventually led to the idea of turning the ‘crowd’ into a formal disability organisation. At the same time, KARINAKAS was just starting the CBR program in the district and approached various organisations in the area (including disability organisations) to invite their participation in the program. It was through this process that KARINAKAS field officers was linked to Agus, which then led to the partnership between KARINAKAS and the ‘crowd’. KARINAKAS was looking for a local disability organisation that could have a leading role in the CBR program, and the ‘crowd’ needed a partnership with a more established organisation in order to get support for turning the informal gathering into a formal and sustainable organisation.

In 2009, KARINAKAS organised a workshop through which FPDB as a disability organisation was officially established. In this workshop, KARINAKAS officers facilitated the initial members of FPDB to develop the vision and mission of the organisation. The vision was to be an organisation that can promote the independence, equality and the fulfilment of the rights of PWD, so that PWD can achieve their personal and social wellbeing. This vision was translated into five missions including: (a) advocating the rights of PWD, (b) building the capacity of PWD in order to foster their economic independence, (c) advocating accessible health services for PWD and their families, (d) improving educational attainment of PWD and their families, and (e) creating opportunities for PWD to develop their talents, especially in the area of arts and sports. In addition, the workshop resulted in the appointment of Agus as the coordinator of FPDB.

Forty people who were interested in joining FPDB attended the workshop. Some of them were from the villages where the CBR program was implemented. These initial members of FPDB come from various backgrounds. In terms of their educational background, this organisation would attract the interest of those who had not finish their primary school as well as those who were university graduates. This diversity was also reflected in their occupation such as farmers, NGO workers, high school students, and those who are usually called *pekerja serabutan* (an Indonesian idiom to call those who do not have a steady occupation, mainly doing various types of short term informal jobs such as casual construction labourer, shop assistant, and running a home-based micro business). Due to the prevailing discriminatory education and employment system in Indonesia, the majority of FPDB members are *pekerja serabutan*. Most of the members are in their mid-thirties, except one member who is a grade 12 student and few members who are in their fifties. In terms of the types of disability, the majority of the members have physical disability (i.e., amputee)

and only a few have sensory disability (i.e., low vision). One third of the FPDB members have become disabled because of injuries sustained in the 2006 earthquake.

The diversity of FPDB members is a distinct feature that differentiates this organisation from the other local disability organisations in the area. My observation during the fieldwork suggested that in comparison to the other disability organisations in Bantul district (i.e., the government sponsored organisations and those which are established for a specific type of disability), FPDB tends to be more inclusive, egalitarian and more independent in determining the direction of the organisation. Such characteristics enable this organisation to be more creative and non-conventional in their activities. A notable example of their creativity was the participation of FPDB in the Independence Day Carnival in 2009.

Celebrating the Independence Day of Indonesia on August 17 is a compulsory annual program for every governmental and public institution in the country. In some districts, including Bantul, one of the regular Independence Day programs is to have a carnival day. The Independence Day Carnival is a day when various groups in the community join a parade that goes around the CBD area. Each group usually dresses up in attractive costumes that symbolise the identity of their group, or wears traditional attire, which represents a particular ethnic group in Indonesia. On this day, each group competes with each other in having the most attractive attire or street performance. As the day is an official public holiday, the carnival always draws a big crowd who come to see the parade. The usual groups participating in the carnival are primary and high school students, village-based women's organisations, village-based youth organisations and civil servants. FPDB was the first local disability organisation joining the carnival.

During my interview with FPDB members, many of them recalled the participation in the carnival day with a great fondness and pride, especially in relation to the particular 'story' that was chosen to symbolise the group. To represent their group, FPDB members chose to

impersonate the characters of a popular Javanese mythology, namely the story of *Punakawan*. The main characters of *Punakawan* are four men with disabilities who are often depicted as a clown or ignorant commoners who use humours or mockery to convey life wisdom. Many people like the story because of its comical but witty and subversive characters. In the *Punakawan* story, the disability of the characters often becomes a source of ridicule yet the characters are highly regarded as a symbol of wisdom and truth.

FPDB members chose to impersonate the characters of the *Punakawan* story for they symbolise their rejection of the common view of disability as an object of ridicule. For FPDB members, the subversive characters of the *Punakawan* story represent their aspiration to develop FPDB as a disability organisation that promotes a ‘subversive’ view on disability. FPDB used the story to challenge the common practice in their society that positions the impairment of PWD as the defining feature of their personhood. Instead, this organisation wanted to emphasise that every person with disabilities has his or her own ability, talents and potentials as illustrated by each character in the *Punakawan* story.

The participation of FPDB in the 2009 Carnival Day became the highlight of the organisation for that year. Not only because FPDB was the first disability organisation participating in the event, but also because the participation encouraged this organisation to be involved in several other public actions on that year. One of the public actions was organising a demonstration in front of the district parliament house on December 2009. In this demonstration, they demanded the district government to develop a district-level disability act which had not been available at that time. During the demonstration, a member of parliament invited them to go inside the Parliament building to present their aspirations. However, they refused the invitation because the parliament building did not have any accessible entrance. Instead they asked the parliament member to sit with them at the front yard of the parliament



building as a way to emphasise their protest on the normalised discrimination that they experience.

Other than organising occasional public actions, from 2009 to 2013, FPDB did not have many regular activities. Moreover, at that time the organisation did not have a steady source of funding. However, the members of FPDB still frequently met in informal gathering sessions throughout the years. 2013 became a momentous year for this organisation when its members had the idea of initiating an assistive device service centre. The idea came from the shared experience of some members of FPDB who use a wheelchair. When their wheelchair is not working properly, there was no place in the district that could repair it. Buying a new wheelchair is often impossible because their limited financial capacity and the fact that the health insurance provided by the Indonesian Government does not cover the payment of assistive devices. Two members of FPDB happened to have the skills to repair wheelchairs as they had experience working as mechanics in a bicycle service shop. Initially, they just offered their help to FPDB members. Through the word of mouth, other PWD who are not the members of this organisation gradually started to ask for their assistance. It was this situation that brought up the idea of initiating a wheelchair service centre.

In collaboration with KARINAKAS, FPDB officially launched the wheelchair service centre in 2013. The financial assistance from KARINAKAS enabled this organisation to rent a place that functions both as the service workshop and the office of FPDB. The establishment of this service centre has provided a job opportunity for five FPDB members who are employed as the mechanics and administration staff. With the income from this service centre, FPDB can pay the members who work at the workshop and save some of the profits as organisation funds.

Although there are only five members who are involved directly in the workshop, the establishment of this service centre has brought observable impacts which positively affect

many of its members. One of the impacts is the ownership of an office that has changed the dynamic of the social interactions among FPDB members. Before having the office, the interactions and meetings between FPDB members were more irregular. Since having the office, FPDB is able to organise a regular monthly meeting. The regular monthly meeting is typically used to present the financial report of the wheelchair service centre or other income received by the organisation (e.g., occasional donation from individuals or organisations), to discuss about upcoming events which are relevant for this organisation to participate (e.g., seminars, training programs or public actions on disability), and to exchange information which is particularly relevant for PWD (e.g., new regulations in accessing health insurance provided by the government for PWD).

Other than enabling FPDB to have a regular monthly meeting, the office has also become an important meeting point that creates an opportunity for the members to have more frequent constructive interactions. Every day after the workshop is closed at about 3 pm, there are always members (at least 3 to 5 people) who stop by at the office to have a chat. Sometime they just gather to have a laugh at each other joke or to play chess. But at other times, the conversations can contain an informal discussion about disability issues, life philosophy, and the socio-political trends in the country. Such an informal gathering usually last for about two hours. It is in this kind of gathering that Agus and Ilham (the most influential persons in this organisation) often share their progressive views on disability.

As the customers of the wheelchair service centre are increasing, FPDB are becoming more well-known in Bantul district and the surrounding areas from which the customers come. Eventually, this development drew some media attention. The profiles of the organisation, and some of the members, appeared in a number of local and national mass media. As a result of this media attention, on December 2014, FPDB was selected by the Office of the Indonesian President as one of the community based organisations which were

granted supporting funds from the Indonesian President. Representing FPDB, Agus and Ilham attended the ceremony in the Presidential Palace. Receiving this grant has become another important moment for this organisation.

The grant from the Indonesian President allows FPDB to expand the services offered in the wheelchair service centre. Other than repairing wheelchairs, the service centre is now able to manufacture a modified motorcycle for PWD. Due to the poor public transport, motorcycles are the most popular mode of transport in Indonesia. Therefore, having a modified motorcycle provides crucial mobility assistance for PWD. Supported by KARINAKAS, some of the FPDB members attended a training program to acquire the required skills for providing such a service. When I visited the service centre 10 months after I conducted my fieldwork, they had even manufactured a modified motorcycle for customers from other provinces in Indonesia. In my meeting with Agus in August 2016, he mentioned that FPDB was recently approached by the Department of Health in Yogyakarta province to discuss a partnership opportunity. The Department of Health assessed the possibility of this organisation to become the official partner in providing assistive device repair services for PWD from all districts in the province.

#### **4.5. Chapter Summary**

In this chapter, I introduce FPDB, which has become the site of this current study. FPDB as an organisation was developed in a post-disaster context, which had brought complex socio-economic challenges for PWD in Bantul district, as well as their families. In addition, FPDB as an organisation was initiated as part of a CBR program that was intended to promote the equalisation of opportunities and social inclusion of PWD in every aspect of their personal and social life.

The current development of FPDB indicates that this organisation has been able to draw the involvement of PWD from diverse backgrounds, in terms of their age groups, educational attainments and professions. Furthermore, FPDB has been able to maintain series of activities that manifest its main role as an advocacy group for PWD in the area. This chapter also outlines some patronising practices commonly experienced by PWD in Bantul district, which may further explain the significance of this organisation as an advocacy group.

## **Chapter 5**

### **Research Methodology**

This chapter outlines the research design, strategies and methods applied in this current study. Informed by the social model of disability (Barnes, 2012; Barnes & Mercer, 2004; Oliver, 1997; 2009), I particularly adopted the transformative paradigm in disability research as proposed by Mertens, Sullivan and Stace (2011). This research paradigm suits the aim of the present study, that is to investigate disability organisations as an empowering setting. In the light of this research paradigm, I employed constructivist grounded theory (Charmaz, 2000, 2007, 2009). In this chapter, I discuss how constructivist grounded theory (CGT) may function as a compatible methodological framework for the transformative paradigm in disability research.

#### **5.1. The Study's Commitment to Non-Oppressive Disability Research**

Disability research is a discipline that is marked by a terrible history of dehumanising practices in which PWD were treated as helpless and pitiful study objects. Nowadays, such practices have been condemned, however, developing research models that advocate the rights and dignity of PWD is still an ongoing struggle (Block, Balcazar & Keys, 2001; DePoy & Gilson, 2011; Mackelprang & Salsgiver, 2015; Mallett & Runswick-Cole, 2014; Moore, Beazley & Maezler, 1998; Thomas, 2002). Prior to the mid of 20<sup>th</sup> century, the dehumanising research practices were often disguised as objective and scientific endeavours with normative intentions of improving the life quality of PWD. Contrary to the claim, through such practices, the dignity and humanity of PWD were denied and their oppressive life experiences were further reinforced (Mertens et al., 2011). In most cases, underpinning this kind of research was the individual medical model of disability. This model tended to view disability

as individual abnormalities and illnesses that needed to be rehabilitated by non-disabled experts. Non-disabled physical characteristics and functioning were positioned as the normality toward which disabled bodies need to be adjusted. This model framed PWD as the problem and the object of research. On the other hand, the non-disabled researcher was considered as ‘neutral’ whose political and ethical views on disability did not pose any harmful implications on the life of PWD (Barnes & Mercer, 1997; Stone & Priestley, 1996; DePoy & Gilson, 2011; Mallet & Runswick-Cole, 2014, Thomas, 2002).

With the emergence of the disability rights movement (DRM) and the rise of the social model of disability since the 1960s, the dominance of the individual model of disability has been challenged. Both the DRM and the social model argue that disability is a social problem. They oppose ableism as the underpinning ideology that normalises the oppressions toward PWD by attributing their disadvantages to their impairment (Barnes, 2012; Goodley, 2011; Mallett & Runswick-Cole, 2014; Oliver, 2009, 2013). The social model of disability rejects the victim-blaming approach and asserts that disability is “a social problem requiring education, attitude change, and social adjustment on the part of both abled and disabled people” (Mertens et al., 2011, p.229).

The DRM and the social model of disability have drawn attention to the importance of framing disability research from a social justice perspective (Danermark & Gellerstedt, 2004). According to Charmaz (2011), social justice inquiry refers to;

... studies that attend to inequities and equality, barriers and access, poverty and privilege, individual rights and the collective good, and their implications for suffering. Social justice inquiry also includes taking a critical stance toward social structures and processes that shape individual and collective life (p. 359).

Drawing on this understanding, I adopted strategies of inquiry that assisted me to be sensitive about how factors such as history, power and privilege have influenced the way disability is framed in the Indonesian society. Research with a social justice perspective is

oriented toward the promotion of equality and the elimination of human suffering (Charmaz, 2011; Prilleltensky, 2001). Particularly in disability research, adopting a social justice perspective means ensuring that the present study is not further reinforcing the existing oppressive realities experienced by PWD in Indonesia. Instead, I attempted to conduct a study that is in line with the struggle of PWD for dignity and equality (Goodley, 2011).

Informed by the DRM and the social model of disability, some scholars have attempted to develop alternative frameworks that promote non-oppressive disability research (e.g., Barnes & Mercer, 2004; Mercer, 2002; Watson, 2012). One of such frameworks is the transformative paradigm in disability research (Mertens et al., 2011). Trained in the field of community psychology, I found that this paradigm suited my personal and professional commitment to the core values and principles of community psychology, which include promoting empowerment, eradicating inequality, advocating social justice and understanding as well as challenging social structures and practices that sustain injustice (Nelson & Prilleltensky, 2010; Dalton, Elias & Wandersman, 2007). For this reason, the transformative paradigm in disability research was deemed to be the most appropriate framework for the study as it is consistent with my commitment to adopt non-oppressive models of disability research.

## **5.2. The Transformative Paradigm in Disability Research**

The widening influence of the social model of disability has generated new paradigms for disability research. The resentment toward the alienating approach of the individual medical model of disability has fostered explorations for models of research that place control in the hands of PWD (Barnes & Mercer, 2004; Dowrick & Keys, 2001; Goodley, 2011; 2013; Mercer, 2002; Moore et al., 1998; Tregaskis & Goodley, 2005; Watson, 2012). Oliver (1992), a leading proponent of the social model of disability, argued that without a fundamental

change in the nature of relationship between researcher and the researched (PWD), the risk of reproducing oppressive research practices is imminent. According to Oliver (1992), the change of social relations when conducting research means “researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever they choose” (p. 111). Meeting this ideal requires a research paradigm that enables PWD and non-disabled people to work together in non-oppressive research relations. The transformative paradigm is a framework that has a potential to facilitate such collaboration.

Within the transformative paradigm, disability is regarded as a social problem for both PWD and non-disabled people. Rather than approaching the issue in an “us” (PWD) against “them” (non-disabled) manner, this framework acknowledges the need of working together toward a more just social structure (Mertens et al., 2011, p. 231). Therefore, the transformative paradigm suggests the importance of situating disability research within the broader social justice framework in which members of culturally diverse groups work together in challenging oppressive structures. In a more detailed account, the transformative paradigm is defined as:

... a framework for research in the disability communities that is more attuned to handling diversity within communities, develops solidarity with other groups that are marginalized, and change identity politics to a socio-cultural perspective (Mertens et al., 2011, p. 230)

With its emphasis on diversity, this framework highlights the need for situating disability in its intersections with other social dimensions of discrimination and oppression which may include gender, race, ethnicity, age, religion, national origin, indigenous status and immigration (Mertens et al., 2011). Furthermore, Mertens et al. (2011) argued that translating the transformative paradigm into research practice involves four considerations, which represent the basic assumptions underlying this paradigm. These four considerations are summarised in the following table:



Table 5. The Transformative Paradigm: Basic Belief Systems (Merten et al., 2011)

Basic assumptions		Implications for research
Axiology (the nature of ethics)	Ethical research is characterised by commitment to human rights, social justice, cultural respect, and reciprocal relations between the researcher and the researched.	<ul style="list-style-type: none"> <li>- Being sensitive to the wider socio-historical and political context that shapes the nature of the study.</li> <li>- Being aware of how the nature of the study may accidentally perpetuate the existing human rights violations, injustice, discriminations and patronizing researcher-participant relationship</li> <li>- Recognising diversity within disability communities and the intersections of disability with other relevant dimensions of diversity.</li> </ul>
Ontology (the nature of reality)	<ul style="list-style-type: none"> <li>- Drawing on postpositivism and constructivism, the transformative paradigm assumes that there may be single reality with multiple interpretations ascribed to it</li> <li>- Power inequality may result in the privilege of certain interpretations over the others</li> </ul>	Framing the study as an attempt to investigate various versions of reality and to interrogate whether or not the study supports the values of human rights, social justice, cultural respects and reciprocity
Epistemology (the nature of knowledge and the relationship between the knower and that-which would be known)	<p>The transformative paradigm assumes that:</p> <ul style="list-style-type: none"> <li>- Knowledge is socially constructed and context specific</li> <li>- The knower is not a sterile investigator, her or his personal worldviews need to be acknowledged and critically reflected in terms of how it affects the nature of the study</li> <li>- Knowledge is co-created by the researcher and the researched</li> </ul>	<ul style="list-style-type: none"> <li>- Emphasising the need for researchers to ground their work in the cultural context of the community being studied.</li> <li>- Conducting research in ways that promote trust and correspond to the needs and expectations of the community's members</li> <li>- Striving for adequate cultural competency through immersion in the community and reflecting upon and recognising the researcher's biases.</li> </ul>
Methodology (the nature of systemic inquiry)	Methodological decisions made by considering to what extent the methods facilitate partnership between the researcher and the researched and attune to the relevant dimensions of diversity, the dynamics of power inequalities and socio-historical and political context of the study	Although has no specific set of methods and practises of its own, however, the paradigm endorses a qualitative approach as it better facilitates dialogues between the researcher and the researched.

The basic belief systems described in Table 5 provide the philosophical and ethical guidelines for this study. Drawing on these basic belief systems, I tried to ensure that the present study is consistent with the commitment toward social justice framework and non-oppressive disability research practice. This commitment underpins the methodological choices and my positioning in this study, which are explained in the following sections.

### **5.3. Methodological Approach to Inquiry: Constructivist Grounded Theory**

Generating contextual knowledge about people's behaviours is a concern central to community psychology (Trickett, 1996, 2009). Underpinning this concern is an assumption that individual behaviours are context dependent. Thus, to fully understand the adaptive value of one's behaviour, researchers need to situate this particular behaviour in the context in which it arises (Trickett, 2009). Based on such an assumption, Trickett argues that community psychology research would benefit from methodological frameworks that may generate rich descriptions about "the ways in which the ecological context affects the lives of individuals" (Trickett, 2009, p. 400). In the area of disability studies, Trickett's argument is in line with the understanding of disability as a socio-historically and culturally situated phenomenon.

Aiming to ground the study within the socio-historical and political context of the community, I adopted a qualitative approach. A qualitative approach allowed me to explore how people make sense, interpret or give meanings to their experiences in their natural settings. In addition, the approach enabled me to engage in in-depth conversations with the research participants and therefore nurture relations, which were sensitive to the needs and expectations of the research participants (Creswell, 2013; Denzin & Lincoln, 2011; Frost, 2011; Willig, 2013).

The purpose of this study was to explore the meanings and significance of participating in a local disability organisation from the vantage point of its members. I

specifically examined how this organisation has been experienced as an empowering setting. Drawing on the constructivist tradition, I assumed that people's personal account of their experiences is not an isolated individual construct. Rather, people develop their personal meanings through lenses they draw from the socio-historical and political resources, which are available in their social settings. Meaning making is a contextual process that is embedded in a particular time and space (Burr; 2003; Stam, 2001). In the case of the present study, the historical, political and cultural situatedness of disability in the Indonesian society has a significant impact on how people give meanings to their experiences. Driven by these assumptions, I developed the methodological framework in the light of constructivist grounded theory (Charmaz, 2000, 2007, 2009).

Constructivist Grounded Theory is a method of qualitative inquiry which originated in the grounded theory tradition as developed by Barney Glasser and Anselm Strauss, but with different ontological and epistemological assumptions (Charmaz, 2000, 2007, 2009; Mills, Bonner & Francis, 2006). In its original version, grounded theory tends to reflect the positivist paradigm, which underlines objectivist approaches to research. Within this frame, grounded theory research is generally characterised by a view of reality as an objective entity that can be approached through unbiased data collection. The researcher is positioned as a neutral observer and analyst. According to the positivist tradition, the aim of grounded theory research is to discover a generalisable truth about the phenomenon being studied (Bryant & Charmaz, 2007a, Charmaz & Henwood, 2008; Mills, Chapman & Bonner & Francis, 2007). However, later in its development, influenced by postpositivism and constructionism, different models of grounded theory research have been introduced. One such model is CGT as developed by Charmaz (2000, 2007, 2009).

CGT shares similarities with positivist grounded theory in terms of positioning the methodology as a systematic strategy to build an explanatory framework that explains

relationships among concepts. However, shifting from its positivist roots, CGT rejects the point about discovering an objective generalisable knowledge. Instead, drawing on constructionism, CGT is interested in framing grounded theory as an inductive approach to investigate the construction of meanings through everyday interactions (Charmaz, 2000, 2007, 2009; Mills et al., 2006). In a more detailed account, Charmaz (2000) notes that CGT is an inquiry approach, which assumes that:

...realities are multiple and the viewer is part of what is viewed. Subjectivities matter. Values shape what stands as fact ... Researcher and participants co-construct the data through interaction. Data reflect their historical, social and situational locations, including those of researcher ... Representation of the data are inherently problematic and partial ... [therefore] reflexivity throughout inquiry [is] integral part of the research process ... Rather than aiming for theoretical generalizations, constructivist grounded theory aims for interpretive understanding (p. 366)

With its emphasis on the social nature of reality, subjectivity, meaning and reflexivity, CGT was considered as an appropriate approach of inquiry for this study. CGT allowed me to engage with diversity within disability communities and take into account the intersections of disability with other dimensions of diversity. This methodology also enabled me to investigate various meanings of disability and to interrogate how the meanings perpetuate or challenge the socio-cultural system that underlines the oppression of PWD in Indonesia. It is this emphasis on interpretative understandings of a phenomenon that makes CGT consistent with a social justice framework.

According to Charmaz (2011), CGT suits the social justice framework because the exploration of contextual meanings of a phenomenon enables a researcher to investigate implicit meanings and actions that underline oppressive practices. By attending to context, positions, discourses, meanings and actions, CGT can generate better understandings of “...how power, oppression, and inequities differentially affect individuals, groups, and categories of people ...[and] reveal links between concrete experience of sufferings and social structure, culture, and social practices or policies” (p. 362)

Drawing on the key features of CGT, I argue that this methodological framework is conceptually compatible with the transformative paradigm in disability research. I particularly outline two points that indicate how these two research approaches may become a complementary combination.

Firstly, informed by constructivist tradition, these two approaches assume that knowledge is socially constructed and context dependent. Consequently, both emphasise the importance of conducting research in ways that are responsive to the wider socio-historical and cultural context in which the study phenomenon is situated (Charmaz, 2007, 2009; Mertens et al., 2011). While promoting the importance of contextual research practice, the transformative paradigm in disability research does not necessarily outline specific sets of methods for conducting such research. This point suggests how CGT may complement the implementation of this research paradigm by providing explicit guideline for collecting and analysing data using an inductive approach. With such an approach, CGT allows researchers to collect and analyse data without imposing prior theories. Instead, CGT creates possibilities for researcher to uncover theories, which are grounded in the particularity of the participants' experiences and their social ecology (Charmaz, 2007, 2009).

Secondly, influenced by the constructivist tradition, both the transformative paradigm in disability research and CGT view that research is a co-constructive process that reflects the relationship between the researcher and the research participants (Charmaz, 2007, 2009; Mertens et al., 2011). Therefore, both approaches emphasise the importance of recognising and acknowledging the subjectivity of the researcher and how it may impact on the research process. CGT as a methodological framework provides specific techniques for identifying the researcher's subjectivity. For instance, through the technique of memo writing, researchers are encouraged to document their own prior knowledge and assumptions, as well as to recognise how these may impact on the data collection and analysis process (Charmaz, 2006).

While CGT provides relevant techniques to operate the understanding of research as a co-constructive process, this methodological framework may not specifically outline how to translate such understanding in the context of disability studies. This point indicates how the adoption of the transformative paradigm in disability research may sharpen the way CGT can be utilised in disability studies.

The transformative paradigm in disability research encourages researchers to be more sensitive with, and explicitly address, the issue of power in knowledge production (Merten et al., 2011). The issue of power in disability studies is particularly related to the question about the role and position of PWD in a research project. Interrogating the extent to which PWD have control over the course of the research project is a crucial step to address the issue of power in disability studies (Barnes & Mercer, 2004; Moore et al., 1998). Therefore, in reflecting their own subjectivity, researchers need to ask how their prior knowledge and assumptions on disability may influence the way they engage with PWD who are involved in the research project. Does the researcher hold specific assumptions that may reinforce patronising views and attitudes toward PWD? To what extent does the researcher privilege the voice and lived experiences of PWD in the research process? Interrogating such questions is instrumental to enact more critically the understanding of research as a co-constructive process (Moore et al., 1998).

How the combination of these two research approaches guiding the data collection and analysis process of the current study is detailed in the next chapter. The following section discusses how I addressed the issue of researcher subjectivity, particularly in regard to my position as a non-disabled person.

#### **5.4. Researcher Positioning**

According to Schwandt (2000) social inquiry should not be considered merely as a method of knowing. More than that, as a practice of transforming others' experiences into

public knowledge, social inquiry implies moral and political responsibilities. Particularly in the transformative tradition, research practices generally aim at dismantling and transforming unjust social practices (Mertens, 2008; Mertens, Holmes & Harris, 2009; Mertens, et al., 2011; Romm, 2015). Drawing on this understanding, researchers should not take objective-disinterested attitudes toward their research topic. Instead, researchers are encouraged to be aware and open about how their subjectivity may underline particular views of human agency and how such views may raise particular moral and political implications (Schwandt, 2000). Adopting this approach, this section presents my exploration of my own social positioning as a non-disabled person undertaking a research in the field of disability studies.

The role of non-disabled researcher has been an important issue in disability research (Goodley, 2011; Stone & Priestley, 1996; Symeonidou & Beauchamp-Pryor, 2013; Tregaskis & Goodley, 2005). The problematic position of non-disabled researchers reflects the long history of oppressive research practices experienced by PWD. In the shadow of ableism and the dominance of individual-medical model of disability, disability research has been marked by the patronising approach of non-disabled researchers. Such an approach has generated research practices, which are characterised with the dominating control of non-disabled researchers. PWD are positioned as anonymous passive objects. They are excluded from the research processes other than being asked to provide access to their body for examination or to respond to the researchers' directive questions. Through this kind of research, the power hierarchy that places PWD as an inferior group is reproduced. In addition, the supremacy and privilege of non-disabled researchers are reinforced, along with ableism as the underpinning ideology (Goodley, 2011; Stone & Priestley, 1996; Symeonidou & Beauchamp-Pryor, 2013; Tregaskis & Goodley, 2005).

Informed by the social model of disability, the patronising research practice as described above has been challenged by the emancipatory approach to disability study

(Barnes 2001, 2003, 2004; Barton, 2005; Mercer, 2002, 2004; Oliver, 1997). Aiming for research practices that respect rights and dignity of PWD, the emancipatory approach advocates the idea of partnership between PWD and non-disabled people. According to this approach, such a partnership can be achieved when non-disabled people shift away from the patronising view that positions them as the expert or the saviour. Non-disabled people need to assume that they are part of the problem, which should be changed, and this change can only happen through solidarity with PWD (Dowrick & Keys, 2001; Goodley, 2011; Tregaskis & Goodley, 2005).

The emancipatory approach as described above provided the general orientation of how I positioned myself in this study. This approach encouraged me to be critical with my own social identities along with the privileges and disadvantages that come with them. As a non-disabled researcher, I am at risk of being ignorant of the marginality and discrimination experienced by PWD because of my embeddedness in an ableism driven society. On the other hand, as a woman who lives in a strongly patriarchal society and being part of a religious minority group in the country (Catholic), I have on-going experiences of being marginalised or discriminated.

Belonging to marginalised and dominant groups, I am aware of how marginalisation and discrimination can be reproduced through mundane attitudes and acts, as well as how these impact upon people's wellbeing. In addition, as a psychologist who was trained and works in Indonesia, I am aware that I may be at risk of reinforcing pathologising approaches to disability considering that such approaches have remained dominant in this country. On the other hand, my training as a community psychologist in Australia has introduced me to a set of values and principles that encourage me to be sensitive with issues of power and privilege and how these may manifest in the reproduction of marginalisation and discrimination.



Continuously bringing this awareness into the research process was a critical part of how I practiced my commitment to non-oppressive disability research.

Maintaining awareness and openness of my own subjectivity by adopting a reflective approach to research was part of my attempts in developing more genuine relations with the research participants. Such awareness might enable me to minimise the risk of practising an exploitative research relationship. Exploitative research relations can be reproduced through various ways. One of them is through the process of othering. Krumer-Nevo and Sidi (2012) explains that the risk of othering happens when through her or his interpretations, a researcher is portraying research participants as “the other who is essentially different, and translating this difference into inferiority” (p. 299).

The absence of reciprocity in the research process is one of the ways through which othering is operated. As researchers, “we ask for revelations from others, but we reveal little or nothing of ourselves; we make others vulnerable, but ourselves remain invulnerable” (Behar as cited in Fine, Weis, Weseen & Wong, 2000, p. 109). Krumer-Nevo and Sidi (2012) suggest that being aware and reflective of one’s own feelings, experiences and history can help a researcher to avoid the risk of othering. By looking inward to her own history and position, a researcher is enabled to recognise the similarities and differences between her and the research participants. In addition, they argue, “this experience of simultaneity between difference and sameness is the source of solidarity” (p. 307).

Engaging in a qualitative inquiry entails a task of interpreting and representing research participants’ stories. When the power imbalance between the researcher and the researched is not adequately addressed, interpretations and representations may result in a process of othering the research participants (Fine et al., 2000). The risk of othering underlines the importance of considering knowledge production as a relational process. This point is captured in the notion of the episteme of relatedness (Montero, 2007, 2012).

According to Montero (2007), “the episteme of relatedness considers that knowledge is produced within relations and by relations. Therefore, the construction of knowledge resides not in the individuals, but in the relations between individuals” (p. 526). This episteme of relatedness corresponds well with the theory of symbolic interactionism that underpins constructivist grounded theory. Symbolic interactionism assumes that people create meanings through social interactions with one another (Jeon, 2004). This understanding reminded me that my interactions with the research participants play a crucial role in shaping the course of the study.

Driven by the understanding that knowledge production is a relational process, I took efforts to minimise power imbalance and the risk of othering. These efforts include:

- Willingness to question and problematise my subjectivity.
- Making critical reflections of how my subjectivity influences the way I interact with the research participants and their identities.
- Making my subjectivity visible to the readers.
- Making efforts to acquire cultural competency that meets the research participants’ expectancies.
- Minimising the disruptions that the study may cause on the research participants’ routine.
- Engaging with the research participants in dialogical conversations.
- Being more sensitive and mindful in the choices of language.

Considering the listed efforts above, therefore, reflexivity is central in this study. As generally suggested, reflexivity in this study involves a process of exploring my subjectivity (i.e., values, experiences, interests, beliefs, political commitments and social identities) as well as the research epistemology (i.e., assumptions on knowledge and knowledge production) underpinning the study (Bryant & Charmaz, 2007b; May & Perry, 2014; Willig,

2013). Both aspects of reflexivity were scrutinised to understand how these have shaped the course of the study. I operated the process of reflexivity by keeping notes of my reactions, questions, hunches and assertions, which emerge throughout the research process. The reflective aspects of this study are not presented under a separate heading. They are integrated into the report and discussed in the appropriate context.

Engaging in the process of reflexivity may provide both the researcher and the readers with a better insight about the study. However, doing reflexivity also has its own risks. When the inclusion of the researcher's subjectivity slips into a self-absorbed process, the study may silence the research participants' voices. In such a situation, instead of adding a critical understanding, reflexivity can manifest as a mechanism for establishing and asserting the researcher's authority (Fine et al., 2000). Being aware of this risk, I regularly shared my reflections with the research participants as well as with peers who have relevant academic background as a way to critically interrogate my notes, hunches and questions.

Reflexivity allows a study to be experienced as a transformative process for the researcher (Bryant & Charmaz, 2007b; Engward & Davis, 2015; Hall & Callery, 2001; Watt, 2007). By critically reflecting her interactions with the research participants and their stories, a researcher may gain insight of how to better develop the study. This process was evident in the present study as my interactions with the research participants and their stories have changed the course of the study. This point is detailed in the next chapter in which I describe the fieldwork process.

## **5.5. Chapter Summary**

Social exclusion experienced by PWD in Indonesia is also reflected in research settings. Adequate reports on disability are still a rarity, let alone studies that put forward critical approaches to disability (Liu & Brown, 2015). This situation is a call for both

theoretical and methodological explorations that can promote disability studies, which are more responsive to the struggle of PWD in Indonesia. Addressing this call, I grounded this study's methodology on the transformative paradigm in disability research as proposed by Mertens et al. (2011). This paradigm provided a platform for me to view knowledge as a constructive process that requires a critical stance in addressing the issues of power in knowledge production.

In addition to this paradigm, I also adopted CGT. CGT is considered as an appropriate methodology since it provides technical strategies, which are compatible with the epistemological and ethical assumptions that underpin the transformative paradigm in disability research. Combining CGT and this paradigm is also considered instrumental in producing situated and contextual theories on disability as these two methodological frameworks assume that knowledge is socially constructed and context dependent. The next chapter discusses how this methodological orientation is translated into methods of data collection and analysis.

## **Chapter 6**

### **Research Method**

In this chapter I provide an account of the methods of data collection and analysis utilised in the study. Firstly, I outline the fieldwork process. In the next section, I describe the profile of the research participants and the procedures used to invite their involvement in the study. I then detail the sources and process of data collection. I conclude this chapter by presenting the stages and techniques of data analysis employed in the study.

#### **6.1. Initiating the Fieldwork Process**

Prior to undertaking the PhD program, I had been working in a university which provided me with opportunities to be involved in a number of research and community projects. Through such activities, in the early of 2013, I was connected for the first time with KARINAKAS, a local NGO which is based in Yogyakarta Province, Indonesia. As an institution, KARINAKAS is owned by the Indonesian Catholic Church and part of the Caritas International (a Catholic humanitarian agency). Many of their programs are funded by donation from the Caritas International network such as Caritas Germany, Caritas Italy and the Catholic Organisation for Relief and Development Aid or CORDAID. Despite its association with the Indonesian Catholic Church, KARINAKAS is operated as a secular organisation (KARINAKAS, 2011; Suharto, 2011).

KARINAKAS has mainly worked in the area of disaster risk reduction. In partnership with a number of local communities in Yogyakarta Province and its surrounding areas, this NGO has been interested in developing local communities' capacity to mitigate and overcome the risks of disasters. The CBR program that was implemented in the Bantul District was one of the community-based projects managed by this NGO. A number of faculty members from

the university where I worked were involved in the early stage of this program, in their capacity as consultants to the KARINAKAS staff. I was not directly involved in the project, but the partnership between these faculty members and KARINAKAS had provided me with opportunities to meet and interact with the staff of this NGO. Through these interactions, I learned about their CBR programs, including the one that was implemented in the Bantul District.

The discussions with KARINAKAS staff had developed my interest to study the issue of community participation in the implementation of their CBR programs. From their field experiences, I learned about the complexity, paradoxes and challenges that emerged in the interactions between KARINAKAS and the partnered local communities. Inspired by such observation, I shared with KARINAKAS staff my intention to pursue a PhD program and my interest in conducting research, which is based on one of their CBR programs. At that time, the CBR program in Bantul was the latest program in KARINAKAS and there had been no study about it. Considering this situation, the CBR program manager suggested to me to do a study based on the CBR program in this district.

I maintained my correspondence with KARINAKAS staff after officially enrolled in the PhD course, in July 2013. Initially, I developed my study proposal by focusing on the issue of community participation. I was interested in investigating the experiences, thoughts and reflections of the local people who participated in the implementation of the program. At that time, I had known that PWD are among the local people who were involved in the program. However, at that stage, I did not have the awareness that the study needed to be particularly situated within the context of disability studies. I also did not have the insight that I needed to specifically focus my study on the FPDB as one of the key local organisations that were involved in the CBR program. It is therefore the Plain Language Statement (Appendix

1) and Consent Form (Appendix 2) for the participants mainly covered general information about investigating the local people's experiences with the CBR program.

The awareness that I need to focus my study on FPDB came later, after I started the fieldwork process and had more intensive interactions with the PWD who were involved in the program. Prior to the fieldwork process, I was reluctant to situate the study within the disability framework. My reluctance stemmed from my insecurity as a non-disabled person. What do I know about being disabled? What if I accidentally do more harm to them through my research? What if I cannot contribute much for their struggle as much as what they would possibly do for my personal development? Driven by this kind of question, I avoided engaging with the core issue of the program. At that time, I thought I did justice by thinking that only PWD who have right and competency to do a study on disability. However, as I started to interact more with the PWD who were involved in the program, and engaged with the readings on the social model of disability, I became aware that through my reluctance I have instead reproduced the marginalisation of PWD.

Through my interactions with the PWD in the program, I realised that by avoiding the issue of disability, I had reinforced the marginalising assumption which views that disability is the problem of those who have disability. I was unable to see that as a non-disabled person who is embedded in an ableism-driven society, I am part of the problem. In addition, by running away from my own vulnerability, I had reiterated the expert-centred assumption which views that a credibility of a researcher is determined by her expertise to help and save the research participants. I failed to see that as a collaborative process, research should be experienced as a transformative setting for both the researcher and the research participants. Driven by this awareness, I changed my approach to the study.

The ethics application for the study was approved on September 29, 2014 by the Victoria University Human Research Ethics Committee (VUHREC). Comments and feedback

from KARINAKAS's staff became one of the considerations in developing the research ethic application. As an organisation with seven-year partnership with the local community, KARINAKAS was well placed to offer constructive advice to ensure the appropriateness of my fieldwork plan to the local context and its cultural protocol. KARINAKAS agreed to vouch for me and facilitated access to the potential participants. In order to ensure that the study was conducted in culturally appropriate ways, the CBR manager in KARINAKAS agreed to allocate time for a monthly meeting with me to discuss and to provide feedback about the fieldwork process.

Following the ethics approval, I started my fieldwork by the end of October 2014. In the beginning of the fieldwork, I had meetings with KARINAKAS's staff and management board to get better understanding on the latest development of the program in Bantul. Afterwards, I started to join any community activity related to the CBR program, which were located in five villages. I visited the fieldwork site for five to eight hours almost every day. In general, my daily routine consisted of attending KARINAKAS staff meeting, doing archival study in the KARINAKAS office, and participating in any CBR activity that happened on that day. The activities included community workshops, meetings with local government staff and visiting families. Sometimes I spent a whole day in one village, some other times I went to two or three villages in a day, depending on the community activities that happened on that day. Including in the daily routine was having informal conversations through activities, which were not directly related with the study such as going out for meals, having after office drinks and attending gathering invitations.

My first interviews were mainly with community health cadres who were involved in the CBR program in their capacity as a resource person in their village. All of them are women and none of them has disability. The interviews with these women provided me with a better understanding of the broader socio-cultural context of the villages. Such an



understanding was instrumental to develop my early observation of how disability issues have been generally responded in the villages. Later on, through one of the regular coordination meetings organised by KARINAKAS, I was introduced to a member of FPDB. The meeting was attended by key actors and organisations that were involved in the implementation of the CBR program. FPDB was one of such organisations.

Following this introduction, toward the end of November 2014, I started to make connection with FPDB. Starting from informal visits to their office, gradually I became a regular participant in their daily activities. The activities included attending their meetings, participating in their group projects and spending hours for hanging out in their office. It is these interactions that raised my awareness to shift the way I approached the topic of the study and consequently to amend the ethics proposal.

Before the fieldwork, I assumed that the data collection would be looking at how different groups in the community (which are identified as the stakeholders of the CBR program) gave meaning to their participation in this program. I aimed to explore how different social actors in the community (i.e., PWD, local governments, and community members) responded to this program, which was initiated by an external agency. With such a question, implicitly, I positioned these different groups in an equal position to each other. At that time, I thought my study would be investigating the tensions between the internal actors and the external agency in relation to the notion of community participation in a CBR program.

However, during the fieldwork, I became aware that with such an assumption I was oblivious with the fact that those groups, which were identified as the local stakeholders, were not equal to each other. Particularly through my interactions with FPDB members, I became aware that the relations between these different stakeholders reflected the way disability as a form of social injustice has been reproduced, maintained or challenged in this community.

This thought became my point of departure to shift the approach I was going to use in developing the dissertation. I made the change by investigating the notion of participation from the vantage point of the local people who participate in FPDB. The data gathered from the other groups were used as a background against which the voices and experiences of FPBD members were situated and analysed.

## **6.2. Research Participants**

Payne (2007) argues that research samples in qualitative studies, including within the tradition of grounded theory, are generally selected purposively. Purposive sampling allows researchers to target specific groups or individuals who have relevant knowledge and experience of the topic being investigated (Payne, 2007; Willig, 2013). Such a consideration suits the nature of qualitative research, which generally aims to investigate subjective meanings or understandings of a phenomenon from the vantage point of a particular group of people within a particular context (Willig, 2013).

In line with this understanding, I purposively selected the research participants based on their involvement in FPDB. I started to individually invite the participation of FPDB members in the study after I had been in frequent contacts with them. Prior to the recruitment process, I had participated in some of their activities, including attending their monthly meetings. Having involvement in their activities provided me with an opportunity to better understand about who might be interested to participate in the study. Likewise, this process allowed the members of FPDB to be more familiar with my presence in the organisation and to know more about my research project and my personal backgrounds before I started to invite their participation in the study. Such a process is considered instrumental to address the issue of power imbalance between researcher and the research participants which is a key consideration in a study informed by constructivist grounded theory (Mills et al., 2006).

After I became more familiar with their activities and obtained deeper understandings of the social dynamic within the organisation, I started to individually approach the members of FPDB for the possibility of participating in the study. The process resulted in 18 members (six women and 12 men) consented to participate in the study. The mean age of the participants was 37.9 (range 19 – 55). Fourteen participants live with a physical disability and four of them are non-disabled. Their educational background range from those who not finish primary school to those who are university graduates. Their occupations include home-based micro business owners, farmers and those who do not have a steady occupation. Only four of them work in formal sectors. Eighty percent of the participants have been involved in FPDB for approximately five years. The rest of the participants have joined this organisation for less than five years.

Furthermore, I also invited individuals who were actively involved in the CBR program, which became the catalyst for the development of FPDB as a disability organisation. The interviews with these individuals were intended to generate deeper understandings of the meanings and significance of FPDB as an empowering setting by portraying more accurately the broader context in which this organisation was initiated. These individuals were KARINAKAS staff (the external agency which initiated the CBR program) and community members who were actively involved in the implementation of the CBR program.

This process resulted in four KARINAKAS staff expressed their interest to participate in the study, as well as 10 community members and two village officers from the villages where the CBR program was implemented. I used the data collected from these individuals mainly to obtain additional background information about FPDB and disability issues in the community. Therefore, the data obtained from these individuals were not reported as part of the main findings of this study, as presented in chapter 7 and 8. The two findings chapters exclusively report the data obtained from FPDB members who participated in this study.

### **6.3. Data Collection**

#### **6.3.1. Approach to interviews.**

One of the characteristics of constructivist grounded theory (CGT) is its emphasis on the exploration of contextual meanings and interpretative understandings of a phenomenon through everyday interactions (Charmaz, 2000, 2007, 2009, 2011). In addition, CGT assumes that meanings and interpretative understandings generated in a study reflect the co-constructive interactions between the researcher and the research participants. As such, CGT inclines toward data collection methods, which enable the participants to share their subjective understandings and experiences of the phenomenon being studied through co-constructive conversations with the researcher. Having adopted CGT, I utilised semi structured interview as the data collection method.

I used semi-structured interview because the non-directive nature of this method provided me with more flexibility to develop or adjust the conversations based on the situations and issues emerging in the interviews (Willig, 2013). Such flexibility was instrumental in exploring the contextual meanings and interpretative understandings of the phenomenon being studied from the vantage point of the participants. As argued by Allen (2011), a non-directive approach to data collection promotes dialogues between the researcher and the research participants as well as allows the voices of the research participants to be heard with minimum filtering. In addition, applying a non directive approach to questioning may minimise the issues of power imbalance as the approach is more likely to allow the research participants to have some influence over the direction of the conversation (Mills et al., 2006). While offering flexibility, the use of semi-structured interviews also provided me with a general guideline to ensure that a same basic line of questioning was applied for each participant and the conversations were consistent with the research question (Patton, 2002).

Furthermore, by applying a consistent basic line of questioning, I was able to make comparison across interviews in order to identify the emerging pattern of results.

The interview schedule guiding the data collection is presented in Appendix 3 and 4. I prepared the draft of the interview schedule before I started the fieldwork by referring to the relevant literature and my preliminary discussions with KARINAKAS staff as the agency that introduced me to the site of the study. I then revised and finalised the interview schedule after I had started the fieldwork for several weeks and gained deeper understandings about FPDB as well as the CBR program that facilitated the development of this organisation.

The interview schedules for FPDB members included a series of questions, which were focused on exploring the meanings and significance of this organisation for the participants (e.g., How did you become involve in FPDB? What do you value most from this organisation? What are your future aspirations for FPDB?). For the interviews with KARINAKAS staff and community members who were involved in the CBR program, the questions were centred around the implementation of the program and their general views on disability issues in the community (e.g., How was this program initiated? How did you become involve in the CBR program? What are the challenges in dealing with disability issues in your community?)

As I used semi-structure interview, I did not apply this interview schedule as a rigid protocol. Rather, I used the interview schedule as a general guideline, therefore, I could modify the questions or the order of questioning to accommodate new understandings or issues emerging in the conversations with the research participants.

### **6.3.2. Interview process.**

Two thirds of the interviews were conducted in the homes of the participants. Only few interviews took place in the office of KARINAKAS and FPDB for the convenience of the

participants. Before commencing the interviews, each participant was given a plain language statement (Appendix 1), informed about their rights as a research participant, and asked to sign a consent form (Appendix 2). The duration of each interview ranged from 30 to 90 minutes depending on the discretion of the participants and the extent to which they wished to share their experiences and reflections. Most of the interviews were digitally recorded with permission from the participants, except for one interview as requested by the participant.

I conducted the interviews by using both *Bahasa Indonesia* (the Indonesian national language) and *Bahasa Jawa* (the local language of Javanese), depending on the preference of the participants. Generally, in most parts of the conversation, the participants used *Bahasa Indonesia* and occasionally switched to *Bahasa Jawa* to express particular thoughts, emotions or nuances, which could not be adequately translated into *Bahasa Indonesia*. For example, some of the participants made a reference to the term *sungkan* in explaining their involvement in the CBR program. *Sungkan* is a Javanese term, which refers to a mix of emotions (i.e., fear, shame, respect), which usually underlies the feeling of inferiority that emerges when someone has to deal with a figure of authority (Purwoko, 2001). *Sungkan* cannot be easily translated to *Bahasa Indonesia* as the term is rooted in the peculiar social hierarchy that governs social interactions in the Javanese cultural system. In such a situation, I used *Bahasa Jawa* to probe or follow up the responses of the participants.

The use of local language in the interviews was both beneficial and challenging due to the hierarchical nature of Javanese language. Javanese language consists of two levels of linguistic styles that reflect the emphasis of Javanese culture on the role of social hierarchy (Guinness, 1986; Mulder, 1996)). These two levels of linguistic styles are *Kromo* and *Ngoko*. *Kromo* is the linguistic style that should be used when the context of communication emphasises the role of respect and politeness (Guinness, 1986, Mulder, 1996). For example, *Kromo* is the expected language in formal community gatherings or when people talk to

persons who are perceived of having higher social status (e.g., young people to elders, community members to village officers). *Ngoko*, on the other hand, is the linguistic style that is supposed to be used when people are communicating in informal and egalitarian contexts, such as in the conversation between people from the same age group. The use of *Ngoko* in a non-egalitarian context of communication (e.g., young people who are using *Ngoko* to speak to elders) is generally considered as being rude (Guinness, 1986, Mulder, 1996).

I found that the use of Javanese language in the interviews could facilitate the communication of culturally specific expressions, yet, the hierarchy of this language also posed a unique challenge. In the interviews with the participants who were older than me, I used *Kromo* when there was a need to communicate in local language. The use of *Kromo* was culturally appropriate in such a context, yet due to its formality, I found that using *Kromo* also created further constraints for both the research participants and myself in engaging in dialogical conversations. Consequently, the use of *Kromo* required me to make efforts to mitigate the risk of the interviews becoming too formal and reducing the capability to have dialogical conversations with the research participants.

To address the formal atmosphere that might be created by the use of *Kromo*, I generally started the interviews by having a conversation about topics, which were unrelated to the subject of the research such as the participants' personal interests or hobbies. In addition, I usually took these 'warming-up' conversations as an opportunity to share about my personal background. I noticed that my willingness to be open about my personal background was often followed by the spontaneity of the participants to ask me some questions about the study or about myself. I found that such a conversation was useful to minimise the formality of the interviews, which might limit the depth of the data elicited in the interviews.

While the use of *Kromo* created a particular challenge around the issue of formality, I found an opposite situation with the use of *Ngoko*. In the interviews with the research

participants who were in the same age group or younger than me, I used *Ngoko* when there was a need to communicate in local language. Due to the informality and egalitarian tone of the language, I found that the use of *Ngoko* created fewer challenges for both the research participants and myself in engaging in dialogical conversations. I noticed that with the use of *Ngoko* the participants appeared to be more relaxed in communicating their thoughts and reflections as the egalitarian tone of the language somewhat minimised the social distance between the research participants and myself.

This experience of navigating the interviews in a particular linguistic context makes me concur with Charmaz (2006) who argues that an interview in grounded study is a contextual and negotiated process. Instead of positioning interviews as a neutral process, she argues that “an interview reflects what interviewers and participants bring to the interview, impressions during it, and the relationship constructed to it ...both participants’ and interviewers’ past and immediate identities may influence the character and content of interaction” (p. 27). This understanding of an interview as a contextual and negotiated process had raised my awareness of how my social status might influence the dynamic of my interactions with the research participants. Particularly, such an understanding encouraged me to be aware of how my identities (i.e., as a woman, non-disabled person, a doctoral student) might elicit particular perceptions that potentially amplify the issue of power imbalance in research relation. This point was evident in how some of the participants reacted to the interviews.

During the interviews, there were some instances in which the participants made a remark about their status as an ordinary villager (e.g., “I am sorry if my answers are not satisfying, I am just an ignorant villager after all”). On one level, such a remark might simply be an expression of politeness or humility, but it might also reflect a complex interplay of various factors that influence the way the participants perceived and responded to the



interviews and the interviewer. The remark reminded me about the importance of taking into account factors such as the long history of Indonesian patronising political system, which tended to place villagers in an inferior position (Schwarz, Tyas & Prawitasari-Hadiyono, 2014). For years, villagers in Indonesia were conditioned to have little confidence in voicing their opinions or aspirations independently (Bebbington et al., 2006). Such remarks also encouraged me to be cautious of the possibility of participants perceiving the research as a hierarchical activity, which places the research participants in a subordinate position to the researcher, due to the research participants' level of academic attainment (Mills et al., 2006). Drawing on these considerations, throughout the interview process I made attempts to ensure that the participants experienced the interview process as a respectful and non-judgemental conversation such as by being mindful with the choice of vocabularies I used in the interview.

The need to maintain a critical awareness of how my identity might influence the interview process was even more crucial in the interviews with the PWD who participated in the study. As argued by Moore et al. (1998), even well intentioned research projects may still risk of reproducing the oppressive practices toward PWD when the researchers fail to “acknowledge and understand the damage that non-disabled people can do to disabled people's lives through research” (p. 90). One of the ways whereby research practices may manifest as a subtle oppressive practice toward PWD is through the presence of prejudicial attitudes toward disability. The researcher may hold prejudicial attitudes toward disability without she or he realising it (Goodley, 2011). It is this understanding that encouraged me to maintain awareness of how, as a researcher, I might be at risk of reproducing prejudicial attitudes toward PWD through the way I conducted the interviews.

As a non-disabled person embedded in a society, which tends to normalise oppressions against PWD, I am aware that I may be insensitive in recognising how prejudices against disability have been subtly reproduced through everyday interactions (Tregaskis &

Goodley, 2005). To minimise such a risk, I used interview memos to note my thoughts and reflections that I gained throughout the interview process. Maintaining interview memos had helped me to be more aware of how prejudicial attitudes toward disability might be unintentionally reproduced through the way I interacted with the research participants. Below is an excerpt from one of the interviews, which exemplifies how the conversation with the research participant encouraged me to reflect on my assumptions and prior knowledge, particularly in relation to my position as a non-disabled researcher:

Just because something is made by a *difabel* person, sometimes it is overly appreciated. Say you go to a food vendor owned by a *difabel* person. Honestly you think her food is just so so or lack in hygiene, but when she is asking you how's the food, you say something really nice about it. You say that her cooking is very good. You are afraid that being honest about the food will hurt her feelings. Because if something is made by a *difabel* person and the quality is not good enough, people usually still say that it is good enough. *Difabel* people are not appreciated for what they create but because of their impairment (Ilham, male, FPDB coordinator)

Ilham did not direct his comment to me personally but what he said prompted me to write an interview memo in which I interrogated my position as a non-disabled person and how it afforded me a particular view, attitude and behaviour toward disability. I started to question the extent to which I had been reinforcing this kind of patronising attitude through the way I conducted the interviews with the PWD who participated in the study. Having such a memo had encouraged me to be more mindful in conducting the subsequent interviews to ensure that the PWD who participated in the study did not find the interviews as an experience, which reiterated and reinforced the existing prejudices against disability.

Other than the issue of researcher reflexivity, ensuring theoretical saturation is another measure of adequate data collection in a grounded study (Charmaz, 2006). According to Charmaz (2006) theoretical saturation in data collection is about ensuring the suitability and sufficiency of the data to confirm the emerging theories in the study. The concept of theoretical saturation requires a researcher to continue the data collection process until further

interviews are no longer generating new emerging theory (Willig, 2013). It is for this reason that I conducted interviews with several participants on more than one occasion. Conducting follow-up interviews with particular participants allowed me to refine and elaborate the emerging constructs from the initial interviews and confirm the saturation of the data. Furthermore, I concur with Allen (2011) who argues that follow-up interviews may maximise the participants' voices and representation in the study. As discussed in chapter 5 (Methodology), such a process suits my orientation toward the social justice framework which views research as a process for fostering solidarity and advocating the voices of the marginalised groups (Mertens et al., 2011).

I tended to conclude an interview when the key issues raised in the conversations had been sufficiently discussed or when the conversations no longer generated any new insights. At the end of each interview, I invited the participant to ask any further question about the study or to share any comment and concern related to the interview process. At this point, I found that instead of raising any question, comment or concern directly related to the study, at the end of an interview, majority of the participants tended to ask me some questions related to my PhD journey (e.g., how did I get the study opportunity? what would I do after finishing the PhD program?) or my experience of living abroad. Such questions were often followed by the participants asking for my opinion on some personal or professional issues, which were considered as the area of expertise of a psychologist. In the interviews with the members of FPDB, when the interview ended, I was often asked to share about how disability issues have been generally addressed in Australia. I found that having such a conversation was useful to generate a sense of reciprocity with the research participants which is instrumental to establish a more non-hierarchical relationship (Mills et al., 2006)

### 6.3.3. Fieldnotes.

While interviews provided the primary data, I used fieldnotes as a source for secondary data. In the fieldnotes, I documented two types of additional data, which are descriptive observational notes and reflective notes. With the descriptive observational notes, I made a detail account about the activities that I participated in as an observer, such as attending meetings, seminars or training programs. In these notes I usually included the agenda of the activity, the participants, as well as the processes and discussions involved in the activity. The reflective notes documented the impressions, thoughts, reflections that I had throughout the fieldwork process whether in relation to the activities in which I participated, the conversations that I had with various individuals and the general observation of what happening in the field. Usually, I made the entry for the fieldnotes at the end of the day after I went back home from the study site. I rarely made a note on the spot in order to avoid disconnection from the people with whom I interacted with or from the activity that took place on that day, except in particular activities in which taking note would not pose such a risk (e.g., being an audience in a seminar or training program).

I found that fieldnotes could serve several functions including providing context and nuance for the primary data collected through the interviews, as well as documenting the evolution of my understanding about the phenomenon being studied. The reflective notes provided me with hunches, preliminary ideas and insights that are useful to refine the process of theoretical sampling as well as to develop codes and abstraction during the data analysis process. Below is an excerpt of a reflective entry from the fieldnotes, which later provided me with an idea of how to code particular data from the interviews:

Memo

Initial interview with Ilham

He mentioned several times the issues of mentality: the ‘demanding mentality’ and the ‘waiting for help’ mentality. For him, accessibility should not be start by demanding others to create accessible environments. Instead, it should be started by firstly changing the mentality of *difabel*. Where and how does he get this way of thinking? (17.12.2014)

Informed by this note, in my follow-up interviews with Ilham, I included questions, which enabled me to have further conversations and reflections about the issues of mentality that he raised. Later on, during the data analysis process, this note contributed in developing *Countering the aid mentality phenomenon* as one of the sub-categories generated in the study.

#### **6.4. Data Analysis**

Regardless of the debates concerning the different perspectives within grounded studies, there are some general characteristics, which specify the data analysis process in a study informed by grounded study (Tan, 2010). One of the similar characteristics is the view of data analysis as an iterative and recursive process which is conducted since the beginning of data collection process and throughout all the stages involved in producing the final theorisation of the research findings (Hawker & Kerr, 2007; Thornberg & Charmaz, 2014). Drawing on this understanding, I started the analysis process at the commencement of the interview process. I used the reflective notes that I made in the end of an interview to start developing my initial analysis of the data, which influenced the course of the subsequent interviews.

As noted by Thornberg and Charmaz (2014), each perspective in grounded study presents different guidelines for conducting data analysis. Yet, generally data analysis in a grounded study involves the processes of transforming descriptive data into theoretical concepts, which “produce a systematic representation of the participant’s experience and understanding of the phenomenon under investigation,” (Willig, 2013, p. 77). Generally, the data analysis includes the process of systematically and rigorously scrutinising the data in order to identify the units of meaning or categories which best represent the experiences of the participants. These categories are then transformed into theoretical concepts through the process of constant comparative analysis in which all categories and the supporting instances

are repeatedly compared to each other in order to clarify the links and integration between categories and to verify the adequacy of the final theoretical concepts (Charmaz, 2006; Willig, 2013; Thornberg & Charmaz, 2014). It is this discussion that provided the guidance for data analysis in this study. I detail the implementation of each stage involved in the data analysis process in the following sections.

#### **6.4.1. Transcription.**

Verbatim transcription of each interview was conducted shortly after the interview completed. The interviews were transcribed into MS-Word documents by a professional transcriber who is a native speaker in both *Bahasa Indonesia* and *Bahasa Jawa*. The assistance from the professional transcriber was required as I sometimes conducted two interviews in one day and I needed to have the transcriptions ready during the fieldwork process in order to start the initial data analysis process.

I read and re-read closely each transcription for several times while listening to the digital recording of the interview to ensure the accuracy of the transcription. This process enabled me to immerse in the data as well as became attuned to the contextual meanings of the conversations. I did not translate the transcriptions into English immediately after completing the interviews as I found that working with the original languages used in the interviews enabled me to maintain closeness to the data and capture the nuance of the conversations. I translated the transcriptions into English when I started to develop the interpretative codes of the data as explained in section 6.3.2.

Verbatim transcription was also conducted to the interviews with additional informants (i.e., KARINAKAS staff and community members who were involved in the CBR program). However, the data obtained were not further analysed to generate conceptual

categories. The next stages of data analysis were applied only to the data resulted from the interviews with FPDB members.

#### **6.4.2. Coding.**

In grounded study, data analysis starts with the process of coding which refers to a systematic process of sorting, interpreting and analysing the interview transcriptions in order to identify the patterns of results emerging from the data (Charmaz, 2006; Thornberg & Charmaz, 2014; Willig, 2013). Consistent with the inductive nature of grounded theory, I conducted the coding process without applying preconceived codes to the data. Instead, I created the codes subsequently by defining what I see in the data (Charmaz, 2006).

Although the coding process was conducted inductively, in the light of constructivist grounded theory, I acknowledge that codes do not solely represent what may be emerging in the data. Rather, codes also reflect the subjectivity of the researcher. Different researchers may see different things in the same data. Drawing on this understanding, I considered coding as an interactive process of describing the subjective realities of the participants as well as applying analytic insights to the data which reflect my own assumptions and expectations as the researcher (Charmaz, 2006; Willig, 2013).

Following Charmaz (2006) I conducted the coding process in two phases, which are, initial and focused coding. I conducted both of the coding processes manually as the size of the sample allowed me to do so without risking the quality of the coding process. As argued by Basit (2003), a researcher may choose manual coding over electronic coding when the size of the project is suitable and the process “allow the researcher to communicate and connect with the data to facilitate the comprehension of the emerging phenomena and to generate theory grounded in the data” (p. 152). I found that the use of manual coding enabled me to have a greater intimacy with the data as I could work directly with the printed transcriptions.

In the initial coding, I used *Bahasa Indonesia* to create codes. I found that working in the original language used in the interviews enabled me to be more sensitive in recognising the nuances of the conversations. I used English when I conducted the focused coding as well as when I started to develop the conceptual categories. Each coding process is described in the following sections.

#### **6.4.2.1. Initial coding.**

The initial coding was conducted line by line by highlighting sections of the text (words, sentences or a complete paragraph), which resonated with the phenomenon being studied. For each highlighted sections, I then made a condensed descriptive label, which captured the essence of the participants' narration. Some of the descriptive labels were in the form of 'in-vivo' labels (i.e., using the participants' own words). Such labels assisted me to stay close to the participants' intended meanings and lessen the likelihood of imposing preconceived ideas to the data (Charmaz, 2006).

Although the focus of initial coding was to develop descriptive labels that most accurately represent the participants' narration, the process often elicited thoughts or impressions, which encouraged me to look at the data beyond what were explicitly narrated by the participants. Therefore, as I conducted line-by-line coding, I also made notes on the thoughts, impressions and comments that emerged along the way. As suggested by Charmaz (2006), such a practice is useful for approaching the data more critically and analytically for the notes may enable the researcher "to see actions and to identify processes" embedded in the participants' narration (p. 51). I found that the notes provided me with hunches and insights, which were useful for developing more conceptual codes in the next coding process (focused coding) as discussed in the following section.



#### 6.4.2.2. Focused coding.

Focused coding was the stage in which I transferred the descriptive codes into more analytical or conceptual codes. As outlined by Charmaz (2006) the process of focused coding is more directed and selective as it uses the most significant or frequent initial codes to sort, synthesise and organise large amount of data (Charmaz, 2006; Charmaz & Thornberg, 2014). When undertaking focused coding for this research, I moved across all interviews in order to identify and compare initial codes that had similar meanings. I then created an analytical or conceptual code, which could capture the essence of those initial codes. For example, I created a selective code ‘togetherness’ which comprised a series of initial codes that reflected the participants’ positive evaluation of FPDB as a space where they can have meaningful connections with others. These initial codes included ‘FPDB as a pleasant gathering’; ‘meeting good friends’; ‘the joy of doing things together’; and ‘connecting to similar others’

The following table illustrates the process that I followed in conducting the initial and focused coding. The excerpt presented in this table was taken from an interview with one of the FPDB members when I asked her about the values she places on being part of FPDB.

Table 6. The Process of Initial and Focused Coding

Transcription	Initial Codes	Focused codes
<p><i>Interviewer:</i> Along the way, what do you value about being part of FPDB?</p> <p><i>Luna (pseudonym):</i> It makes me think that, <u>despite my limitations, I realise that I can be a useful person for others around me.</u> That’s the thing ... That’s the thing that I really appreciate about my life. Also, <u>now I have more experiences, I learn organisational skills,</u> how to manage an organisation, <u>I gain knowledge.</u></p>	<p>Changing the way of thinking about herself</p> <p>Being a useful person for others</p> <p>Gaining experiences Developing skills</p> <p>Building knowledge</p>	<p>Participating in FPDB as mindset changer</p> <p>The valuable meaning of being a contributing community member</p> <p>Facilitating capacity building</p>

### **6.4.3. Developing conceptual categories.**

Following the focused coding, I started the process of transforming the focused codes into conceptual categories. A conceptual category is a higher level of abstraction that groups similar focused codes, which share central features or characteristics (Willig, 2013). As argued by Browne (2004) developing conceptual categories is an iterative process in which the researcher meticulously compares the patterns of result emerging in the data with the theoretical insights which “may be derived from the researcher’s imagination, intuition, thinking or previous knowledge about the topic” (p. 640).

According to Charmaz (2006), the end results of developing conceptual categories are a number of concise abstractions with general reach and analytic direction that can explicate ideas, events or processes being investigated in the study. Conceptual categories provide the researcher with abstract scaffolding upon which she or he may develop the theoretical discussions that address the research question (Charmaz, 2006; Willig, 2013). As such, conceptual categories need to be rigorously verified to ensure their adequacy in generating the final theoretical discussion of the study through the process of constant comparative analysis. Finalising conceptual categories usually involve the ongoing process of comparing, sorting and resorting, moving and revising preliminary categories along with supporting focused codes until theoretical saturation has been achieved (Charmaz, 2006; Willig, 2013).

Technically, I conducted the process of developing conceptual categories by transferring all the focused codes that I had developed manually into a Microsoft Excel spreadsheet. I inserted the focused codes into the top row of the spreadsheet and the pseudonym of each participant into the left column. Then, I copied and pasted the sections of highlighted text from the electronic copy of each transcription into the appropriate cell in the Excel spreadsheet. This technique enabled me to organise all the focused codes and the supporting quotations into a single document. I then printed out all the spreadsheets and stuck

them together. This process provided me with a visual display that made the process of comparing, sorting and resorting, moving and revising the initial conceptual categories easier. In addition, this process might have increased the accuracy of the conceptualisation process because the display made the similarities and differences across initial conceptual categories became more noticeable.

I started the process of developing conceptual categories by clustering focused codes, which shared similar features. As suggested by Willig (2013), the early clustering was provisional for facilitating the process of on-going modifications and refinements. I repeatedly compared all the clusters until the need to develop new clusters or to rearrange the existing clusters no longer identified. After that, I transformed each cluster into a conceptual category by creating a higher level of abstraction that I found most accurately captured the essence of the focused codes grouped in the corresponding cluster.

I created a conceptual category by constructing a new analytical label that reflected the shared features of the focused codes, which were grouped together in the corresponding cluster. For example, based on the interviews with FPDB members, I created four focused codes which all referred to the same idea about the value of FPDB as a place that provides opportunities to develop their personal capacity. These four focused codes were ‘becoming a source of knowledge and information’; ‘developing practical skills’; ‘expanding network’; and ‘promoting personal growth’. I then grouped together these four focused codes and transformed these codes into a conceptual category by creating an overarching abstraction entitled ‘facilitating capacity building’

In constructing the conceptual categories, I sometime used ‘in-vivo’ labels to name a category. One of the examples is the conceptual category ‘accessibility as mentality’. This wording was derived from the original expression mentioned by one of the research participants. As noted by Charmaz (2006), the use of ‘in-vivo’ labels prove to be useful for

such labels may reflect an innovative term from the participant that eloquently captures the meanings or experiences being discussed in the study.

While developing these conceptual categories, I also conducted the process of memo writing. As suggested by Charmaz (2006), memo writing was a process in which I documented assumptions, reflections, and other considerations, which influence my decisions to construct and arrange the conceptual categories in certain ways. I found that such a practice provided me with useful hunches and insights for developing the theoretical mapping. This process is outlined in the next section.

#### **6.4.4. Theoretical mapping.**

Theoretical mapping formed the last phase of the data analysis process. It was a phase in which I made an attempt to clarify and verify the definition and properties of each conceptual category. In addition, theoretical mapping involved a process in which I mapped out the theoretical links between conceptual categories and how these categories might contribute in explicating the socio-psychological processes investigated in the study (Charmaz, 2006). The process of theoretical mapping enables researchers to more readily identify and refine the emerging theories from the study, which usually constitute the findings sections of a grounded study research (Charmaz, 2006).

Drawing on the constructivist approach, I oriented the process of theoretical mapping toward the production of what is called the “situated knowledge” (Charmaz & Bryant, 2008). With the notion of situated knowledge, Charmaz and Bryant underlines the preference of CGT “to locate their analysis in the specific historical, social, and interactional conditions of their production, rather than constructing concepts abstracted and separated from their origins.” (p. 376). Following this tradition, the theorising process in my study was aimed at generating situated understandings that might explicate the socio-psychological processes

whereby participation in a local disability organisation was experienced as an empowering process within the particular historical, cultural and political context where the organisation was located.

In order to generate situated understandings, it was essential for me to ensure that the theorising process was guided by the data, rather than by imposing an existing theory into the data (Charmaz, 2006). At the same time, however, the theorising process needed to be responsive to existing theories in the field of study. This enabled me to discuss the extent to which the emerging theories from my study supported or challenged the existing theorisations of the topic (Willig, 2013). Drawing on this rationale, I approached theoretical mapping as a process of assessing the adequacy of the emerging theories by considering two factors simultaneously. Firstly, I needed to verify that the emerging theories were firmly grounded in the data. Secondly, I needed to ensure that the emerging theories had analytical power that enabled me to adequately address the research question and contribute to theoretical developments in the area being studied.

I used a diagram to facilitate the process of mapping out the theoretical links between categories and exploring possibilities for further abstractions across categories. Based on these processes I then finalised the theorising process. As suggested by Charmaz (2006), diagrams provide ‘concrete images of our ideas’ that enable researchers to “see relative power, scope and the direction of the categories in [their] analysis as well as connections among them.” (pp. 117 – 118). To illustrate the process, I present below (Figure 1) a diagram that I created for analysing the conceptual categories, which were developed from the interviews with the members of FPDB.

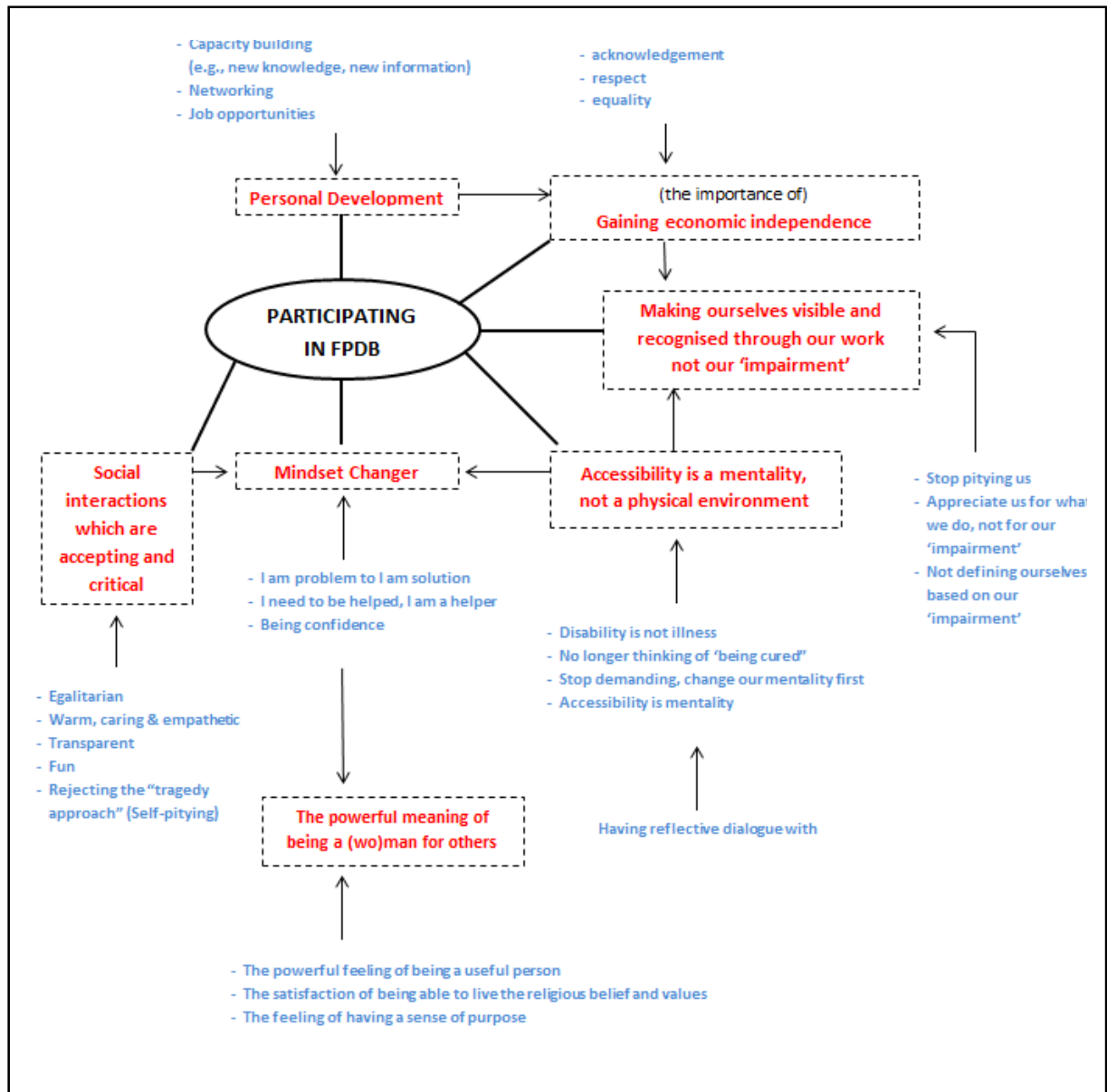


Figure 1. Initial Theoretical Mapping

This diagram captures the initial conceptual categories that I created and how I attempted to systematically draw connections between these categories. Those printed in red and placed in dashed-line boxes are the initial conceptual categories. The use of dashed-line is to indicate the provisional status of the categories. Those printed in blue are the properties or attributes that constituted each category. The arrows represent my preliminary thoughts of how the categories might be connected to each other. I utilised the memos that I created when

I was transforming the focused codes into conceptual categories to explore possible connections between these categories.

This diagram provided me with a visual mapping that assisted me in verifying the theoretical capacity of each conceptual category to explicate the phenomenon being studied, as well as in exploring further abstractions and connections across categories. Guided by this mapping, I then compared the categories to one another as well as the attributes that constituted each category. This stage of data analysis involved the process of going back to the relevant quotations from the interview transcriptions in order to double check the accuracy of the conceptualisations. Furthermore, the process also required me to shuffle and re-shuffle the connections between categories until I no longer identified the need to rearrange the existing connections between categories. This theorising process resulted in the final conceptualisation as presented in Figure 2 below:

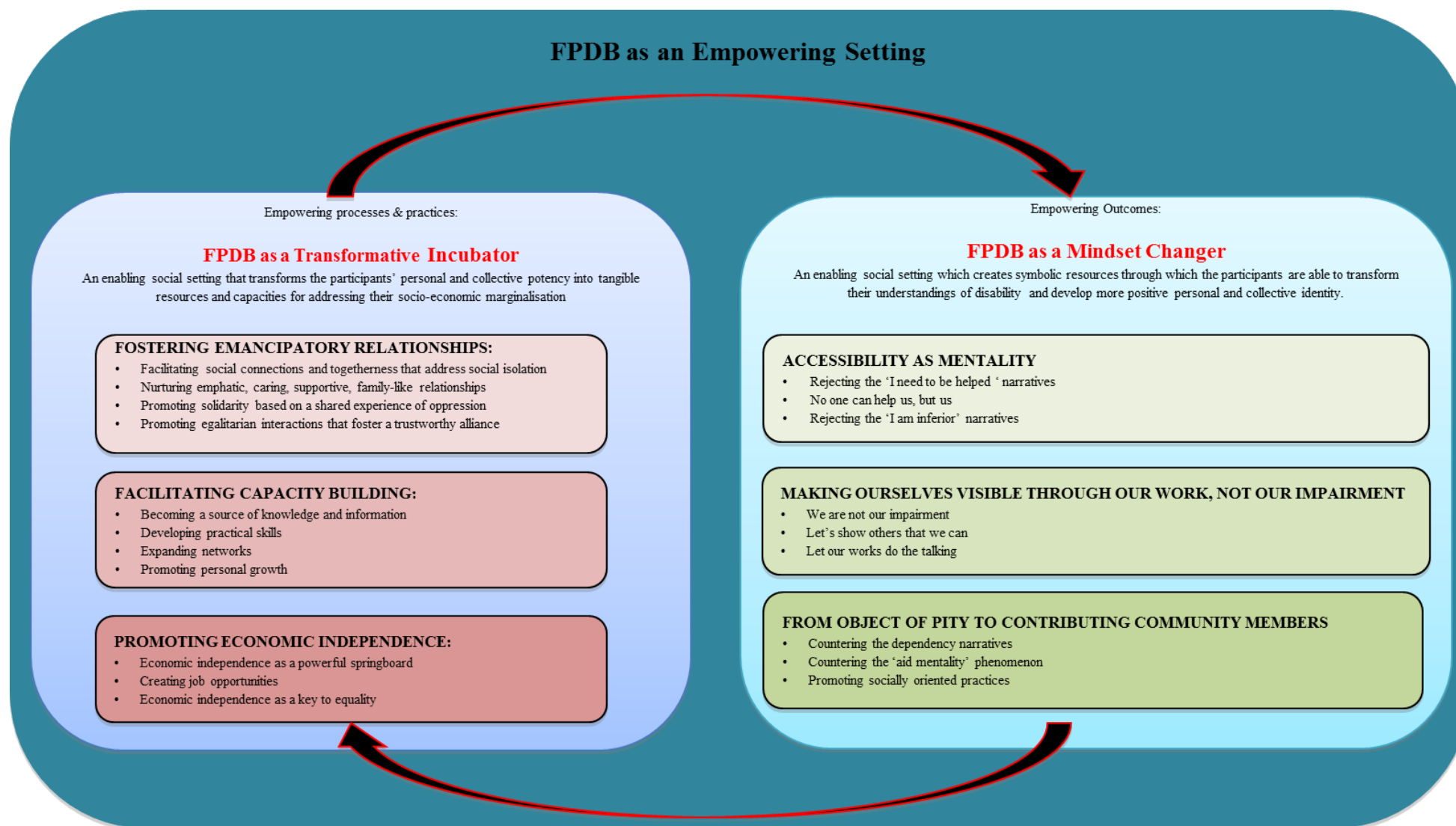


Figure 2. Conceptual Mapping: FPDB as an Empowering Setting



Figure 2 illustrates how I refined the conceptual categories as well as the connections between those categories. This figure also shows the emergence of two new conceptual categories (i.e., *FPDB as a transformative incubator* and *FPDB as a mindset changer*), which were positioned as an overarching conceptual category. The emergence of these two new conceptual categories exemplified how diagramming had enabled me to identify a higher level of abstraction which encompassed the existing conceptual categories. Each conceptual category presented in the figure above is discussed in detail in the next two findings chapters.

## **6.5. Establishing the Credibility of Data Collection and Analysis**

Ensuring the credibility of the method used in collecting and analysing data is just one aspect of evaluating the trustworthiness of qualitative research projects (Willig, 2013). Willig suggests that each aspect, which shapes the final presentation of a research, project, (including the choice of a research problem, the formulation of the research question, the theoretical orientation and so on) needs to be assessed for its rigour and consistency with the epistemological framework guiding the project. She argues that each epistemology requires different measures of establishing research credibility. In this section, I aim to specifically discuss the strategies that I used to establish the credibility of the data collection and data analysis method applied in this study.

The epistemological framework of this study (i.e., social constructionism) as well as my orientation toward a transformative paradigm in disability research provided me with four considerations that I needed to take into account in determining the strategies for establishing the research credibility. As outlined in chapter 5 (Methodology), these four considerations were: (a) the need to ground the study in the particular historical, cultural, and political context of the community being studied, (b) the need to be attuned to the dimensions of diversity and the dynamics of power inequalities that shaped the social context of the study,

(c) the need to frame the study as an attempt to investigate various versions of reality, and (d) the need to conduct research in ways that promote trust and reciprocity (Mertens et al., 2011).

Drawing on these four considerations, I applied the following strategies to establish the credibility of both the data collection and analysis method applied in this study:

1. Establishing familiarity with the context of the study through prolonged engagement

According to Charmaz (2006), having familiarity with the research context before starting the data collection may promote the credibility of the research process because such familiarity may provide the researcher with deeper understandings of the wider social context in which the study is situated. Drawing on such a consideration, I applied several strategies to develop an early familiarity with the study context before I started the data collection process.

These strategies included the process of maintaining regular contacts with KARINAKAS (the agency that introduced me to FPDB), from the conception phase of the study in order to sensitise the study plan with the situation in the field. Furthermore, prior to the data collection, I spent the first several weeks of the fieldwork process to observe the daily situation in the study site as well as to interact with a number of individuals in the local communities. Such a strategy provided me with some preliminary feedback to refine the data collection plan so that the process and the results would be more responsive to the social context in which the study was situated.

I conducted the fieldwork for four and a half months' duration in which I visited the study site on daily basis. This duration enabled me to have a prolonged engagement with the people who participated in the study. Such an engagement also allowed me to observe over time the types of social interactions and activities that took place in FPDB.

## 2. Applying tactics to encourage the openness of the participants

The extent to which a data collection process can generate credible findings is often influenced by the willingness of the participants to openly share their reflections and experiences (Shenton, 2004). This phenomenon reminded me about the importance of making attempts to encourage the participants to share their genuine thoughts or feelings without being fear of having to experience negative consequences due to their honesty. Ensuring that the participants were comfortable to have honest conversations was also important to minimise the likelihood of the participants providing responses, which not reflected their actual experiences, but deemed to be socially desirable responses. Such openness was important to generate data, which were attuned to the dimensions of diversity and the dynamics of power inequalities in the study sites. The openness of the participants might have enabled me to gauge the different or even conflicting perspectives that the participants had in regard to the phenomenon being studied.

I made several attempts to encourage honest conversations with the research participants. These attempts included establishing adequate rapport before starting the interview process and ensuring that the participants were fully aware of their rights. In the beginning of each interview, I discussed with the research participants about their right to withdraw from the study at any point without any negative consequence, as well as their right of having their identity kept anonymous along with explanations about situations that might require me to disclose their identity. Furthermore, I always invited the participant to discuss any particular consideration that I needed to be aware of in relation to the information shared by the participants (e.g., ‘off the record’ type of information).

In order to increase the willingness of the participants in engaging in honest conversations, I also provided the participants with information about the study (e.g., how the findings would be reported, who would have access to the data) as well as my independent status. Since I was firstly introduced to the research participants by KARINAKAS staff, I needed to ensure that the participants did not perceive the study as an evaluation study that I conducted on behalf of KARINAKAS. As argued by Shenton (2004) such information was useful to encourage the participants to share their experiences without fear of jeopardising their partnership with KARINAKAS.

### 3. Organising regular debriefing sessions

Willig (2013) argues that obtaining feedback from credible persons (e.g., research supervisors, colleagues, other researchers) may contribute in increasing the credibility of qualitative research. According to Shenton (2004) the benefits for receiving the feedback of others may include obtaining different perceptions to the study, which may prompt a wider vision in navigating the research process. The feedback may also elicit ideas for having alternative approaches in data collection or analysis as well as helps the researcher to recognise possible flaws in the initial plan of the study (Shenton, 2004).

Other than regularly discussing the research process with my supervisors, I also attempted to obtain credible feedback from peers and other researchers who were familiar with the area of study or the research method that I used. For example, during the fieldwork process, I arranged regular discussion sessions with a local anthropologist who had expertise in the field of Indonesian politics and Javanese culture. As this anthropologist is an academic staff member in a university in Yogyakarta, he sometimes invited some of his postgraduate students to join the

discussions. During the data analysis process, I also shared my preliminary analysis with peers who were postgraduate students undertaking qualitative research projects.

By having these discussions, I was able to obtain some feedbacks that I utilised to refine the data collection and analysis process. For instance, some of the questions asked by the anthropologist and his postgraduate students had provided me with a different understanding about the political embeddedness of the participants' experiences. Such an understanding has helped me to reduce the possibility of analysing the data in a politically naïve way.

#### 4. Ensuring the saturation of data collection and data analysis through constant comparative analysis and negative case analysis

Obtaining the saturation of data collection and analysis is central in grounded study to ensure that the emerging theories are firmly grounded in the data (Charmaz & Bryant, 2008; Charmaz, 2006). Conducting constant comparative and negative case analyses are two strategies commonly used in grounded study to establish the credibility of both the data collection and analysis processes. Constant comparative analysis requires researchers to repeatedly compare “data with data, data with code, and code with code to find similarities and differences” through which the researcher is able to assess the saturation of the data collected and the resulting analysis (Charmaz & Thornberg, 2014, p. 7). Negative case analysis refers to a process of exploring cases that appears to negate the emerging patterns of result in the study (Willig, 2013). In grounded study, examining negative cases usually functions as a way to refine the emerging theories or to provide alternative explanations of those theories (Charmaz, 2006).

Throughout the data collection and analysis process, I applied both constant comparative and negative case analysis as strategies to achieve theoretical saturation.

As I have explained earlier in this chapter, maintaining fieldnotes, memo writing, ‘diagramming’ were the tools utilised to keep track of the ideas and reflections that emerge throughout the process of data collection and analysis. The documented ideas and reflections were then used to facilitate the process of constant comparative analysis.

Furthermore, during the data collection and analysis process, I applied negative case analysis when I identified the emerging of ‘outliers’. For example, during my interviews with the participants, I started to notice the tendency of these participants to highly value the ability of FPDB to create a family-like social setting. However, I then came across with one participant who indicated a negative view on the family-style management applied in FPDB. This participant raised a concern that such a management style may hinder the ability of FPDB to function more professionally. Exploring this negative case helped me to be more critical in interpreting the texture of the participants’ experiences, which was instrumental to develop a more refined theorisation of the findings.

#### 5. Conducting member checking

Member checking is a strategy to increase the credibility of the research by obtaining feedback from the research participants in relation to the findings of the study (Merriam, 2009; Shenton, 2004). I conducted member checking for two considerations. The first was to validate the emerging findings of the study by discussing with the participants about the extent to which the findings accurately represented their experiences and expectations. Second, I found that conducting member checking was in accordance with my commitment to conduct research, which promoted trust and partnership for enabling the research participants to be a part of the analysis process.

I conducted member checking by going back to the study site to meet with some of the participants, ten months after the fieldwork and then again six months later. In the meetings with the participants I shared with them my initial interpretations of the data and then asked for their comments and feedbacks. The responses of the participants indicated that they agree with my initial interpretations. A couple of participants provided additional instances and reflections, which elaborated the initial interpretations.

## **6.6. Reflections on Ethical Issues**

In this section, I discuss my reflections in exercising the practice of ethical research in the particular socio-cultural context within which I conducted the study. Adopting the transformative paradigm in disability research, I am aware that conducting ethical research practice involves complex considerations beyond meeting the basic ethical guidelines in qualitative research (e.g., informed consent, no deception, right to withdraw). As outlined in chapter 5 (Methodology), ethical research practice within the transformative paradigm is associated with commitment to human rights, social justice, cultural respect, and reciprocal relations between the researcher and the researched (Mertens, et al., 2011). By adopting this paradigm, researchers are expected to put these considerations into practice in every aspect of the research process, from the designing phase until the final presentation of the study. As such, developing a comprehensive examination of the ethical aspects of this study may require a discussion beyond the scope of this chapter. In the following section, I aim to discuss ethical issues, which are specifically related to the data collection processes employed in my research.

Despite the availability of basic ethical guidelines, scholars have discussed that conducting ethical research often requires particular considerations, which are specific to the

context of the study and the characteristics of the participants (e.g., Giordano, O'Reilly, Taylor & Dogra, 2007; Guillemin & Gilam, 2004; Kaiser, 2009). The particularity of the context and the participants may generate dilemmatic situations, which raise certain ethical implications and therefore require the researcher to make more nuanced considerations in balancing the research agenda and the wellbeing of the participants (Guillemin & Gillam, 2004; Kaiser, 2004). These arguments were evident in my experience, particularly in relation to the issue of informed consent and respects for the autonomy of participants.

Informed consent implies the responsibility of a researcher to ensure the voluntary nature of the participants' involvement in the research by providing them with adequate and honest information about the research so that the participants are able to make an informed decision to participate in the study (Corti, Day & Blackhouse, 2000). Conventionally, researchers provide signed informed consent forms as the evidence of the participants' consent. At a glance, asking the participants to confirm their consent by providing their signature may seem as a straightforward procedure. Through my data collection experience, however, I learned that asking the participants to sign the informed consent form could sometimes be a complicated process due to the particular socio-political context of the study.

During the data collection process, I encountered the same situation as described by Novianti (2013) who also conducted a study in some local communities in Bantul District. Based on her research, which involved the participation of the 2006 earthquake survivors, she found that signed written forms were not always suitable for documenting the consent of the research participants. Novianti noted that using signed written forms might generate problematic situations due to the negative experiences that some of her study participants had in the post-disaster context. During the post-disaster context, conflicting situations emerged in a number of villages due to the corruption and nepotism found to be present in aid distribution, which resulted in unequal distribution of aid among the villagers. Novianti found



that such a socio-political context had resulted in some of her research participants tended to be suspicious when they were asked to signed a written form, as they were concerned that their consent might be misused to validate corrupt and damaging practices. Drawing on this experience, Novianti argued about the importance of having alternative methods to document the participants' consent, which meet the preference and concerns of the participants.

I became aware of this issue through my conversation with a participant who shared her concern about what she perceived as unjust or unethical practices regarding how aid was being distributed among villagers by the village authorities. This conversation prompted me to be more cautious in communicating the purpose and rationale of asking the participants to provide evidence of their consent. Learning from Novianti's (2013) study, I also discussed with the participants, the possibility of having another method to document their consent, including using verbal recording. Despite this, all of the participants agreed to provide written consent, which to some extent might be encouraged by my willingness to address the concern that the participants might have in regard to providing written consent.

A respect for participants' autonomy was the second ethical issue through which I learned about the complexity of navigating the concept of ethical research practice. Giordano et al. (2007) discussed that the concept of respects for participants' autonomy entails the responsibility of the researcher to respect the choices or preferences of the participants in regard to the terms and conditions of their participation in the study. Through the data collection process, I learned that adhering to this concept might generate a dilemmatic situation because meeting the participants' preferences might be followed by the risk of compromising the other idealistic considerations that I aimed to achieve.

I gained practical exposure about this kind of dilemmatic situation in the context when I needed to balance between respecting the participants' preferences on how they would like the interviews to be conducted and my concern about obtaining credible data. As argued by

Shenton (2004), one of the strategies that may generate credible data is by applying “tactics to help ensure honesty in informants” (p. 66). Drawing on this understanding, I expected that I could interview the participants in a private place without the presence of other person to encourage the participants to talk openly about their experiences. During the data collection process, however, I learned that such an expectation might contradict the preference of some of the participants. Some of the participants indicated a preference to have their family member accompany them throughout the interview process, especially when I interviewed male participants. I was aware that such a preference was related to the social norms and expectation in Javanese culture, particularly in regard to the roles of gender in social interactions (Tickemayer & Pujiastuti, 2012). My commitment to respect the participants’ autonomy required me to take into consideration the participants’ preference for having their family member joining the interview process. Conversely, I was aware that the presence of their family member in the interview might create some barriers for the participants to be able to talk openly about their experiences.

Drawing on these experiences, I concur with Guillemin and Gillam (2004) who argue about the importance of having sensitivity in recognising and addressing “the everyday ethical issues that arise in the doing of research” (p. 263). Their arguments underline the understanding that to conduct an ethical research practice is a situated process, which requires the researchers to be attuned to the wider social context in which the study is located.

## **6.7. Chapter Summary**

In this chapter, I discuss the fieldwork process, methods I used to collect and analyse the data, as well as the description about the participants. I also explain the theoretical and practical assumptions, considerations and expectations that underline the deliberate choice of these methods. Guided by CGT, I choose strategies of data collection and data analysis, which

more readily enabled me to generate, situated and nuanced knowledge about the phenomenon being studied. The constructivist tradition also directed me toward strategies of data collection and analysis, which enabled me to emphasise the subjectivity of the participants. Furthermore, I included my reflections about the attempts that I made to contextualise the chosen method in the particular socio-cultural settings in which I conducted the study.

As a result of the data analysis, I generated two key conceptual categories that explain the overall findings of this current study as presented in the following two chapters. The first conceptual category (i.e., *FPBD as a transformative incubator*) is detailed in chapter 7, followed by the second conceptual category (i.e., *FPDB as a mindset changer*) which is discussed in chapter 8.

As illustrated in Figure 2, the two conceptual categories generated in the current study are not mutually exclusive, but are interconnected. The empowering processes and practices identified in the first conceptual category have produced the transformative outcomes described in the second conceptual category. Similarly, the transformative outcomes presented in the second conceptual category further developed the empowering processes and practices that have characterised FPDB as an enabling social environment. The interconnection between these two conceptual categories and how these two categories as a whole develop FPDB as an empowering setting are detailed in chapter 9 where I present the overall discussion of this current study.

## Chapter 7

### FPDB as a Transformative Incubator

#### 7.1. Introduction

*FPDB as a transformative incubator* is the first out of two conceptual categories that represent the overall findings of this current study. Figure 3 outlines the structure of this conceptual category, along with its constituent sub-categories and attributes. This figure also outlines the organisation of this chapter. I start by examining the overall meanings of FPBD as a transformative incubator. Then, I continue with detailed discussion on each sub-category, which includes relevant quotations from the interviews with the participants.

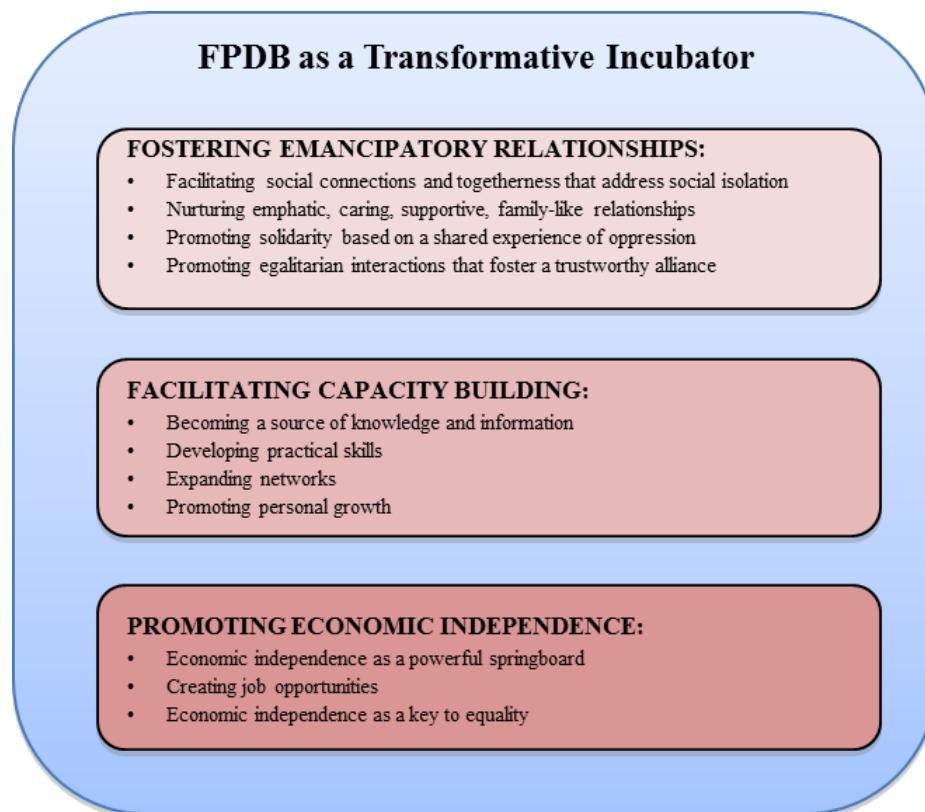


Figure 3. First Conceptual Category: FPDB as a Transformative Incubator

This first conceptual category is particularly concerned with the social processes and practices established in FPDB that have enabled the participants to experience this disability organisation as an empowering social setting. The overall findings of this current study suggest that FPDB has functioned as an enabling social setting by transforming the participants' personal and collective potency into tangible resources and capacities, which are instrumental in addressing their marginalisation. In this sense, the meanings and significance of this organisation as a transformative incubator reflect the way disability as a form of socio-economic oppression has shaped the participants' personal and collective struggle.

Consistent with current reports on disability in Indonesia (e.g., Adioetomo et al., 2014), the participants' experiences have demonstrated that living with disability has exposed them to various forms of discrimination and marginalisation. Against such a backdrop, the potential of FPDB as an empowering social setting centres on its ability to transform the participants' vulnerabilities in the face of a discriminatory social system, into a shared vision and struggle for equality, dignity and autonomy. As a transformative incubator, this organisation has served as an enabling vehicle for the participants to enact their shared vision and struggle. The view of FPDB as an enabling vehicle is reflected in the following excerpt:

I dream that FPDB will grow in the future and we will be able to maintain our sense of connection with each other. I hope that all friends here become more confident in themselves and most importantly, will become economically independent ... I would say that FPDB has grown only when I see that my friends here have become more comfortable with who they are and have the courage to start their own businesses, which involve *difabel* people from their area. For me, that will be the indication that FPDB has grown. Currently, FPDB is growing. We are doing a collective business. But, in the future, when all friends here have become more skillful and financially stronger, they can start their own businesses that share similar visions and missions

with FPDB. In this way, they won't have to be always with FPDB. They can leave FPDB, have their own business and work together with *difabel* people in their area (Ilham, male, FPDB coordinator).

The above quotation was Ilham's reply, when I asked him about his hopes and dreams for FPDB in the future. It was such a reflection that inspired me to consider this organisation as a transformative incubator. His reflection captures the vision shared among FPDB members and the processes that have been made to turn their vision into reality.

As reflected in the above quotation, I found that the participants tended to consider this organisation not as an end in itself, but as a catalyst for envisioning the creation of similar organisations that are led by PWD. The majority of participants believed that the vision and mission advocated by FPDB could generate wider impacts by the development of similar groups in other villages. For example, this hope was expressed by another participant saying:

I will consider FPDB has reached its success when we can spread out our success stories to many more people, not just between us (Puan, female, FPDB secretary).

When I asked her to elaborate what she meant by success stories, she said, "Minimally when our members can have a steady income from what they are doing".

The quotations from Ilham and Puan above illustrate the common hope shared by FPDB members. Like Ilham and Puan, all of the participants expressed a hope that this organisation can function as a place where they can develop and prepare themselves to be a role model for PWD in other villages. Such a hope reflects how this organisation tends to be seen as a medium for the participants to develop themselves as knowledgeable and competent activists in relation to their struggle for achieving equality, dignity and autonomy.

The shared hope of making FPDB as a transformative setting has generated a series of enabling psychosocial processes and practices. Drawing on the meanings that the participants ascribed to their involvement in this organisation, I identified three psychosocial processes and practices that have contributed to the development of FPDB as an empowering setting. These include:

1. Fostering emancipatory relationships.
2. Facilitating capacity building
3. Promoting economic independence.

In the following sections, I discuss how each of these processes and practices speaks of the way in which participation in this organisation has been experienced as a transformative activity. In addition, I also examine how each of these processes and practices reflects the participants' collective struggle for equality, dignity and autonomy within the particular context of Javanese society.

## **7.2. Fostering Emancipatory Relationships**

When I asked the participants about the benefits of joining FPDB, all of them spoke positively and passionately about the social relationships that they have in this organisation. Particularly, they highlighted the nature and quality of social relationships nurtured in FPDB which have provided them with a range of interpersonal benefits including decreased sense of isolation, feeling respected and understood, as well as feeling valued and supported. Furthermore, the participants' reflections suggest that such interpersonal benefits have been made possible by particular relational habits or styles promoted in this organisation. These habits include showing care for each other, preferring egalitarian style of communication as well as emphasising transparency and inclusivity in the decision-making process.

Drawing on the participants' reflections on the nature and quality of social relationships in FPDB, I conceptualised the sub-category of *fostering emancipatory relationships*. This sub-category explains a series of interpersonal processes and practices, which have enabled the participants to experience their social relationships in this organisation as an enabling connection. These interpersonal processes and practices include:

- Facilitating social connections and togetherness that address social isolation.
- Nurturing emphatic, caring, supportive, family-like relationships.
- Promoting solidarity based on a shared experience of oppression.
- Promoting egalitarian interactions that foster a trustworthy alliance.

Each of these processes and practices is detailed in the following sections.

#### **7.2.1. Facilitating social connections and togetherness that address social isolation.**

Across the interviews, all of the participants reported that they highly value FPDB for its ability to facilitate social connections that allow them to interact with other PWD in the area. All of the participants mentioned that togetherness and a strong sense of connection to each other are the two features that they liked most about being part of this organisation:

The strength of FPDB is in its togetherness ... we always have that 'Let's deal with it together' attitude ... whenever we have any concern, we can always talk about it together (Bagas, male, FPDB member).

What I value most about FPDB is its friendliness ... I think all the other things are simply the outcomes of our friendliness (Jatmiko, male, FPDB member).



As mentioned in chapter 4 (FPDB Profile), the togetherness and sense of connection in this organisation have been developed long before FPDB as a formal organisation was established. The majority of the members have known each other since they regularly gathered and had informal discussions in the town square. The regular gathering sessions in the town square had provided FPDB members with a supportive space to share their frustrations in dealing with the pervasive discriminations they experienced, as well as to discuss their aspirations and ideas. The informal and relaxed atmosphere in the gatherings had made people feel welcomed and comfortable to share their feelings and thoughts, which eventually nurtured egalitarian relationships among FPDB members. Such characteristics were maintained when FPDB was then established as a formal organisation.

For FPDB members, it appears that the informal gatherings in the town square have functioned as an important part of what is argued by Sarason (1972, p. 25) as the “before-the-beginning” stage. By this phrase, Sarason argued that the nature and development of a setting is often strongly influenced by the conditions and events preceding the official establishment of a setting, including the patterns of interpersonal relationships among its initial members (Cherniss, 2012). Since the very beginning of their interactions, the initial members of this organisation have encouraged interpersonal relationships, which are welcoming, warm and egalitarian; therefore, such characteristics have eventually become continuous features of FPDB.

Some participants’ experiences indicate that the value of togetherness and a strong sense of connection in this organisation are related to the high degree of isolation commonly faced by PWD in the area. The participants’ experiences suggest that they are often being socially disconnected from their community due to the existence of physical and socio-cultural barriers that have discouraged PWD to be socially active. This sense of isolation was

strongly evident in Jatmiko's experience whose disability was caused by the injury sustained in the 2006 earthquake.

The earthquake happened not long after I finished my high school, so I was still in the age when I liked to go out a lot with my friends. After the earthquake, I just stayed at home for 9 months ... I wanted to roam around but I could only stay at home ... If I wanted to visit my friends, my cousin would take me ... at times I became emotional, wanted to be able to do it by myself ... my sister then trained me [driving a modified motorcycle] ... Thanks God, now I can do it (Jatmiko, male, FPDB member).

Jatmiko's experience illustrates the environmental barrier that has challenged many PWD in their attempts to maintain social connections due to the unavailability of accessible public transportation. In addition, the issue of social isolation can be exacerbated by negative attitudes commonly targeted towards PWD. Such an attitude was reflected in Jalu's explanation when he shared his failed attempt to invite his neighbor who is also a PWD to join FPDB:

Her parent did not allow her to leave her house. Her parent is afraid that when she goes out, neighbours will make fun of her. She used to go out, but then neighbours would say something that caused children afraid of her, something like "Look Dewi is coming, aren't you afraid of her". Dewi is treated as a scary person that made children frightened ... Her parent often tells me, "I feel embarrassed if my daughter goes out, because neighbours often say to their children something like, "Look! Dewi is coming, don't be naughty or she will take you!" (Jalu, male, FPDB member).

It is within such a social environment that all of the participants highly value the social connections that they have built in this organisation. As suggested by some participants, being

part of FPDB has reduced their social isolation and generated solidarity in dealing with the social rejections commonly experienced by PWD.

As explained in chapter 3 (Contextualising the Study), FPDB members live in rural areas where communal solidarity and mutual exchanges are highly emphasised. There are cultural and economic pressures that expect people to maintain their involvement in community activities and rituals, otherwise people may be socially sanctioned (Guinness, 2009; Newberry, 2007). In such a socio-cultural and economic context, there is a high possibility for the participants to experience more acute sense of isolation when they are excluded by their communities.

Being socially isolated may also increase the participants' social and economic vulnerability due to the lack of adequate public services provided by the Indonesian government. In such a political context, people often have to rely on the network of communal exchange and cooperation in their local communities to be able to meet their basic needs (Guinness, 2009; Newberry, 2007). Therefore, being socially excluded may pose greater mental and physical as well as economic risks to the participants.

Situated in the socio-cultural and political context of Javanese society, it becomes apparent that the ability of FPDB to facilitate social connections and to foster a sense of togetherness among its members has played a crucial role in shaping this organisation as an empowering social setting. For the participants, the social connections and togetherness that they have in this organisation have provided them with solace in dealing with the myriad psychological, social and economic difficulties that they have experienced as a result of living in a discriminatory society.

Furthermore, the participants' reflections indicate that participating in FPDB has afforded them a form of social resource in the absence of government and community supports. As a social resource, this organisation has provided the participants with a sense of

safety and feeling socially supported. This finding is in line with the argument of Scotch (2011) which highlighted the vital role of having a supportive social group for PWD as their “functioning is less likely to be effectively supported by the kindnesses of strangers or by distant governmental bureaucracies than by community members with whom they share social ties and common identity” (p. xv). In the following section, I discuss further the meanings of feeling socially supported for the participants.

### **7.2.2. Nurturing emphatic, caring, supportive, family-like relationships.**

In regard to valuing FPDB as a place for initiating and maintaining social connections, the participants frequently associated their involvement in this organisation with positive experiences and emotions of having a compassionate, family-like circle of friends:

FPDB feels to me more like a family and that what makes FPDB distinct as an organisation (Wisnu, male, FPDB member).

FPDB is not simply a social forum. There is a strong sense of sisterhood and brotherhood there. It is like you have a family ... There was one time when FPDB was in vacuum, and I think it was that sense of sisterhood and brotherhood that brought us back and continued our gathering (Tulus, female, FPDB member).

All friends in FPDB are always ready to help each other (Pawestri, female, FPDB member).

There is that strong sense of compassion in FPDB. Whenever there is a friend who is sick, we will immediately inform all the other members and we will go together to visit this friend. If there is a friend who is in grief for having a family member passed

away, we will go together to visit this friend, showing our condolence and support (Amir, male, FPDB member).

The four quotations above illustrate how this organisation seems to be experienced as a supportive family-like setting, which have provided the participants with an empathic and caring relational environment. Feeling well looked after and supported are highly valued by the participants, and in turn, these positive psychological experiences may help the participants in sustaining their sense of connectedness:

When you are facing a hard time, and people come to you, it means you find your family. They are my family. It is easy to find friends when you are having your success ... but friends who stay with you when you are having difficult times, that is something special, and that is FPDB ... that what makes FPDB strong ... they really are my family, although they may not give me anything, any help, but they are on my side, ... they listen to me, and that's where I find a family ... when I am feeling down, I often feel alone. It feels really lonely ... so having friends is really meaningful ... really happy ... when I meet other *difabel* persons it makes me feel that I have many friends, many brothers and sisters (Ilham, male, FPDB coordinator).

There are so many good things that come from joining FPDB ... when I had a hard time, there were so many friends who came to help me. I experienced that myself when my wife passed away. Many friends came to help me. They helped me handling all the things with the hospital ... so many friends showed their care ... that what has made me keen to socialise with the other members, to join them (Amir, male, FPDB member).

Ilham's and Amir's reflections suggest that they have experienced their participation in this organisation as a source of both psychological and practical supports. In this sense, the empowering function of FPDB is manifested in its ability to foster supportive and caring social connections among the participants, which can then function as a meaningful social resource for them.

The psychological benefits of participating in a supportive and caring relational environment for those dealing with the consequences of oppression have previously been identified in various types of empowering settings (e.g., Case & Hunter, 2012; Jorge-Monteiro, Aguiar, Saachetto, Vargas-Moniz & Ornelas, 2014; Seidman & Tseng, 2011). As noted by Case and Hunter (2012), "being able to openly share one's experiences with others who share a similar experience of oppression has the potential to ameliorate current psychological distress" (p. 266). In line with these studies, the experiences of the participants indicate that through their involvement, they have been able to create a source of psychological support which may help them to mitigate the distressing consequences of being socially excluded.

Besides psychologically meaningful, the opportunity to experience this organisation as a compassionate, family-like social circle may also be culturally important for the participants. Situated within the broader context of Javanese culture, the participants' emphasis on the 'family-like' quality of FPDB may particularly relate to how the notion of family is generally constructed in Javanese society. Within the social fabric of Javanese society, roles and values associated with the notion of family have generally functioned as a guiding principle in various social settings, far beyond the narrow context of a family as a biologically related social unit (Shiraishi, 1997).

The emphasis on the notion of family in Javanese culture is conceptualised within the value of *kekeluargaan* or family-ism (Shiraishi, 1997). *Kekeluargaan* refers to a set of

psychological and social attributes, which are considered as the ideal criteria of a fully functioning family. Examples of such attributes include the presence of nurturing roles and protective functioning, emphasis on maintaining social harmony (favorably by avoiding any possibility for direct conflicts and confrontations), and adherence to social hierarchy (Shiraishi, 1997).

The value of *Kekeluargaan* is generally positioned as a core principle in various social organisations, from informal neighbourhood-based associations to professional organisations including government departments and educational institutions. There is a general expectation that every social organisation can function like a family, in addition to its professional roles and duties (Robinson, 2009; Shiraisi, 1997).

The value of *kekeluargaan* explains why community life in Javanese culture tends to be seen as an extension of a family unit (Guinness, 1986, 2009; Koentjaraningrat, 1989). In this sense, people tend to position and experience their locality (e.g., neighbourhood or village) not only as an administrative or spatial unit rather as an intricate web of familial connections that can function as a source of social assistance and protection. Such a connection is generally reproduced and reinforced through routines social activities and rituals commonly organised in Javanese villages, such as the tradition of *selametan* or communal feast. Being involved in this kind of social ritual is highly valued as a way of validating and securing people's position in the web of familial connections that underpins their community life (Guinness, 1986; 2009; Koentjaraningrat, 1989).

Situating the participants' experiences in the Javanese cultural context is instrumental to fully understand the magnitude of psychological and social disadvantages commonly experienced by the participants, as a consequence of being socially excluded from their community. For the participants, being socially excluded may cause them being disconnected from the familial network that underpins the participants' community. As a result, the

participants may have limited access to experience their community as a source of assistance and protection. FPDB has enabled the participants to address such a challenge by creating an alternative web of familial connection that functions as a source of assistance and protection.

The participants' reflections suggest that the role of this organisation as an alternative web of familial connection is nurtured through what I identified as a ritual of compassion, such as by visiting a friend who is sick or in grief, or even by coming to a friend's house without any particular agenda. During my fieldwork, I had a number of opportunities to observe directly such practices. One time, I joined some FPDB members to go to the house of Bagas, a member who also participated in this current study. Bagas invited us to have a meeting and lunch at his place. Later on, when I interviewed Bagas, he recalled positively this visit. He mentioned how happy he was to have friends coming to his place.

FPDB members live in a number of different villages across Bantul District, therefore, the participants often have to travel quite far by using a modified motorcycle to be able to visit one another. Accessible public transport is hardly available. In addition, not all of FPDB members have a modified motorcycle. Usually, those who have a motorcycle will pick up other members who do not have it. Such a situation illustrates the extent of effort that the participants have to make to maintain their rituals of compassion.

Situated in this social ecology of Javanese society, it becomes apparent that as a social setting, this organisation has not only been psychologically important but also culturally meaningful for the participants. By providing a compassionate, family-like social circle, FPDB has created an alternative web of familial connection, which may assist the participants' survival in the social and cultural context of Javanese society.

### **7.2.3. Promoting solidarity based on a shared experience of oppression.**

*Promoting solidarity based on a shared experience of oppression* is the third social process that constitutes the sub-category of *fostering emancipatory relationships*. In reflecting



about their involvement in FPDB, the participants highlighted the opportunities that they have to connect with other PWD who face similar struggles and challenges. The participants' reflections indicate that such opportunities are central in fostering their determination to resist their common experience of being socially excluded:

If you want to encourage a *difabel* person to go out, the encouragement should also come from a *difabel* person. If you want to invite someone who lives with paraplegia, the invitation should also come from a *difabel* person who lives with paraplegia. If it is someone who doesn't live with paraplegia inviting the person, I don't think it will work (Astuti, female, FPDB member).

In relation to the politics of disability in Indonesia, Astuti's reflection particularly points to the existing tendency of treating PWD as passive objects of intervention conducted by non-disabled experts (Suharto, 2011; Thohari, 2007). As explained in chapter 4 where I presented the profile of FPDB, the idea to initiate this organisation was partly driven by the participants' disappointment with how they were treated at a government owned rehabilitation center. Instead of positioning PWD as 'the expert' of their situation, the participants felt that the practices in the rehabilitation centre tended to position PWD as a helpless object of intervention. The participants particularly highlighted the limited involvement of PWD in designing and implementing the programs that were delivered in the rehabilitation centre. Instead, the programs in the rehabilitation center were predominantly designed and implemented by non-disabled staff.

Considering such a background, Astuti's reflection suggests that the value of participating in FPDB is related to the opportunity to encourage and be encouraged by others with whom the participants share similar struggle and challenges. In this sense, FPDB as a social setting provides a contrasting practice compared to the participants' previous

experience at the rehabilitation centre. By connecting PWD to each other, this organisation has become a setting where the participants are acknowledged as ‘the expert’ of their own situation. By creating an opportunity to engage with others who share similar struggle and challenges, joining FPDB has allowed the participants to be a source of encouragement for each other in a way that speaks particularly to their subjective realities.

For those experiencing an oppressive living condition, research has shown that connections with others who undergo a similar situation may help the persons to have their subjectivity and experiential realities acknowledged and validated (Case & Hunter, 2012). Similar with such research, the participants’ reflections suggest the importance of this organisation as a social setting that has enabled them to build meaningful connections with others PWD. This kind of connection has helped the participants to have their personal ordeal validated and promote their sense of solidarity, as illustrated by the following excerpt:

The person may already have it [a sense of solidarity] ... but, we may have it because others passed on that value to us, that value of solidarity ... it comes from habits.

When there is a friend who is in need, we collect money for him. We help him, like that, and it becomes a habit. Initially, perhaps there were only one or two persons who had that kind of attitude, but then it becomes contagious. I hope everyone can have such an attitude (Wisnu, male, FPDB member).

Wisnu’s reflection illustrates how social relationships that the participants have in this organisation have fostered a sense of solidarity with others who share a similar experience of oppression. By describing solidarity as a ‘contagious’ attitude, Wisnu’s reflection underlines the relational nature of empowerment (Rappaport, 1987). Through and within the relationships with others, the participants have been enabled to transform their personal ordeal into a collective struggle. The participants’ reflections indicate that the presence of strategic

others is fundamental in facilitating their personal and collective transformation (Case & Hunter, 2012). In this sense, FPDB seems to be experienced as an empowering setting by enabling the participants to foster a meaningful and genuine alliance.

#### **7.2.4. Promoting egalitarian interactions that foster a trustworthy alliance.**

In reflecting their social relationships in FPDB, the participants frequently cited their enjoyment of having the opportunities to connect with others in egalitarian ways. Drawing on such reflections, I identified *promoting egalitarian interactions* as the fourth process that constitutes the sub category of *fostering emancipatory relationships*. In this section, I discuss the participants' enjoyment of being able to have egalitarian interactions with each other and how such interactions have contributed in promoting a trustworthy alliance.

The participants mentioned that one of the things that have always made them want to come and congregate in the FPDB office (even when there was not any particular agenda), was because they enjoyed a lot the conversations as well as the jokes they shared with each other, as Cahyo recalled it:

I like to hang out with all friends here, having a laugh, ... when we make a joke of each other we never feel offended, though the jokes may seem harsh, so far there has been no one feel offended ... because of our closeness, it feels so comfortable to talk to each other and to make jokes ... never feel bored. Although it may not give any particular benefit, but I like to hang out with all friends here ... simply because it makes me happy, just like that (Cahyo, male, FPDB member).

As mentioned by Cahyo, for an outsider, it might be considered as a waste of time spending hours in what seemed to be an aimless yarn. However, for FPDB members, it was through this kind of conversation that they often learned new or different ways of thinking

about their own and others' experiences, particularly in regard to how disability has been constructed in their community. Ilham provided a detailed account on this point:

It may seem that we're just having a yarn, but we are actually having a talk about the meanings of our life, how we actually like to live our life. We are encouraged to sensitise our feelings ... I might casually ask a friend, "so what did you get by attending the training program at the rehabilitation centre, what differences it made to you?" and he might reply, "I don't know ... Just to kill a time, perhaps" ... like that ... So, I would ask him, "killing time? Is that what you want to do for the rest of your life? Don't you have any dream? A purposeful aim?" ... like that ... so we go back to that very question about the meaning of being human ... when we are having a formal meeting, there will not be such a talk, friends will not be open up about their thoughts or ideas ... but, when we are having a yarn, they will just speak up ...so, it is better to just hang out and have a yarn rather than to organise a formal meeting but there is no idea shared, and people find it difficult to talk about their concerns. But when we are having a yarn, people feel no restriction to share their concerns for there is nothing that they are afraid of ... unlike in other organisations, where you feel afraid to this or that person, so you can't say what you want to say ... so having a yarn will make the situation more relaxed, and in fact as an organisation we were started from a yarn, having a yarn is good. We can talk about anything, about being human, about life, not merely about disability ... we don't want to confine ourselves into a disability box ... after all we are talking as human, not as a *difabel* person (Ilham, male, FPDB coordinator).

Ilham's reflection points to the role of intersubjectivity in the creation of empowering setting (O'Donnell & Tharp, 2012). O'Donnell and Tharp define intersubjectivity as

“psychological commonality that provides meaning in [people’s] lives”, which results from sharing similar experiences and engaging in collaborative interactions (p. 24). In other words, intersubjectivity represents a sense of connection which is gradually built as people engage in shared activities through which they cultivate “their collective history, values, thoughts, emotions and interpretations of the worlds” (p. 24). In this sense, having a yarn and sharing jokes can be considered as a social mechanism through which FPDB members have developed their intersubjectivity. In addition, intersubjectivity has facilitated FPDB members to develop reflective understandings of their shared history, values, emotions and worldviews.

The participants’ reflections indicate that intersubjectivity has also contributed in strengthening their sense of belonging to this organisation. The participants’ experiences appear to reflect Cronick’s (2002) argument which suggests that intersubjectivity may generate a cohesive feeling of ‘we-ness’ by enabling the members of a group to define (or redefine) themselves which may then result in a shared understanding of “we-ness” (p. 538). Similar with this argument, the participants’ reflections indicate that the opportunities to engage in egalitarian social interactions with others who share similar struggle and challenges are central in fostering a trustworthy alliance among them. As reflected in the following excerpt, such an alliance seems to contribute in developing and strengthening the participants’ sense of “we-ness”:

I hope FPDB can consistently advocate us. I hope we are not like many of those who become disabled because of the injury sustained in the earthquake. They show less care once they have recovered from their injury. Once they can walk, they have less commitment. ... I hope in FPDB, we can continually maintain our commitment in advocating *difabel* people. Let’s not be a short life organisation which is passionately developed in the beginning but then dies easily. I hope we can sustain FPDB as long as possible, always make a progress for the benefits of *difabel* people, whether in terms of advocacy or providing care and assistive devices (Astuti, female, FPDB member).

Astuti's reflection above indicates how she values her participation in this organisation as an opportunity to foster a trustworthy alliance. In addition, her reflection suggests that the opportunity to foster a trustworthy alliance is particularly meaningful in relation to the challenging situation that emerged in Bantul during the post-disaster period. Astuti explained that during the recovery process, a number of aid agencies sponsored the development of community-based support groups for PWD in the Bantul District. Many members of these support groups were those who became disabled because of the injury sustained in the earthquake.

Before joining FPDB, Astuti was previously involved in such support groups. She herself has lived with a disability since years before the earthquake. Astuti found that these support groups tended to be short life for some of the members who became disabled because of the injury sustained in the earthquake left the groups once they had recovered from their injury. This experience explains why she highly values her participation in FPDB for it provides her with an opportunity to experience genuine relationships, which then foster a trustworthy alliance. Through FPDB, Astuti has found a contrasting experience to what previously happened in the post-disaster context.

Considering the politics of disability in Indonesia, the opportunities to develop a trustworthy alliance may have a wider significance for the participants, beyond the particularity of post-disaster context. As discussed in chapter 3 (Contextualising the Study), PWD in Indonesia continue to experience pervasive marginalisation and discrimination, despite the availability of legal regulations that acknowledge their rights. Some cases included in chapter 3 illustrate the ongoing discriminative practices commonly experienced by PWD in Indonesia. Such practices may result in a sense of distrust toward the possibilities of having trustworthy relationships that make PWD feel genuinely respected and supported. This kind of background may explain why it is really meaningful for FPDB members to be able to

develop trustworthy relationships among them. In this sense, the enabling feature of this organisation as an empowering setting is related to its ability to promote social relationships that foster a trustworthy and genuine alliance.

For some of the participants, the value of FPDB as a facilitator of trustworthy relationships is evident in the commitment of FPDB coordinators to manage the organisation based on the principles of openness and transparency. Some of the participants expressed their appreciation for the tradition in this organisation to always have an open discussion whenever they need to make a decision. This tradition creates possibilities for all members to have their say about the decision made. Two participants shared this point when I asked them about what they think as the strengths of this organisation:

There is always a transparency. Whenever we have a meeting, it's always open and transparent, like, okay we have this amount of money and we are going to use for this thing about this much and that thing about this much, everything is openly shared. So never ever that something is covered up. Since the first time I joined, that never happened, always transparent (Cahyo, male, FPDB member).

Openness to each other, for example, when we got the grant from the presidential office. You know, that's a big amount of money. If anyone at the board of directors took some of the money for himself, perhaps no one would know, right? But that didn't happen. The amount we got was exactly the same like what was written in the invoice. So, that's what I meant by our openness. I really believe that we have that. Our coordinators are well educated and have an open mind. So, that is what makes FPDB progressive (Among, male, FPDB member).

These two quotations further highlight how meaningful it is for the participants to have trustworthy relationships. The participants' accounts suggest that the value of having trustworthy relationships is not only related with the concept of honesty, but also it represents a sense of equality. By ensuring that every issue is openly discussed and everyone can have a say in the decision making process, FPDB as a social setting has treated equally everyone in the organisation. In this sense, everyone's feelings and thoughts are equally respected and acknowledged. Such a finding is in line with previous studies on community participation (e.g., Balcazar et al., 2012; Radermacher, Sonn, Keys & Duckett, 2010; Ramella & De La Cruz, 2000) which have suggested that participation will be experienced as an empowering activity only when it allows people to have meaningful involvement in the decision making process.

In addition, this issue of trustworthy relationships is particularly important in relation to the financial matters of FPDB, considering that corruption has been a sensitive issue in the local community where FPDB members come from. As discussed in chapter 6 (research method), during the post-disaster context, conflicting situations emerged in many villages in Bantul district due to the corruption and nepotism found to be present in aid distribution (Joakim, 2013; Zaumseil et al., 2014a). My observation during the fieldwork suggested that people still tended to be suspicious when it came to the issue of aid or grant distribution. Such a suspicion was made worse by the long-standing corruptive practices that often occurred in local government institutions and community organisations (Joakim, 2013; Zaumseil et al., 2014a). In this sense, the value of FPDB as a transformative setting may relate to its ability in restoring the members' trust to the possibilities of developing a trustworthy alliance.

Overall, the findings presented under the sub-category of *promoting emancipatory relationships* indicate that the participants have experienced this organisation as a setting where they can develop meaningful social connections and togetherness with whom they



share similar struggle and challenges. Such connections have become a meaningful social resource that provides the participants with care and supports. In addition, the social connections that they develop in this organisation have also generated a trustworthy and genuine alliance, which allows them to experience FPDB as their ‘family’ rather than merely as an interest-based organisation.

While the majority of the participants seem to highly value the ‘family-like’ qualities that characterise this organisation, one participant expressed a different view on this issue:

We still heavily rely on particular persons, so I am afraid if something happens to those persons, what can we do? ... As an organisation, we not yet have a system that manages the structure of FPDB, like a system that regulates the director’s roles, how he should undertake his tasks, so that when the current leaders need to be replaced, we are not vulnerable ... Our current ‘family-like’ style of organisation may have negative effects. Perhaps in the future we will have more money, and if by that time we not yet have an adequate organisational system, I am afraid something bad will happen. Like the Suharto era, you know, it may be like that. But I hope it won’t be like that (Wisnu, male, FPDB member).

In his reflection Wisnu made a particular reference to the Suharto era, a political era in Indonesian history, which was infamous for its corruptive and nepotistic practices. His concern suggested a complex issue, which may challenge FPDB as an organisation in the future. I discuss further this issue in chapter 9 where I present an overall discussion for the findings of this study.

### **7.3. Facilitating Capacity Building**

*Facilitating capacity building* is the second sub-category that characterises FPDB as a transformative incubator. This sub-category encompasses all of the participants’ reflections,

which refer to similar ideas of experiencing this organisation as a setting that has facilitated the development of knowledge and various practical skills.

As described in chapter 5 (the Profile of FPDB), the main activities of this organisation are running a wheelchair service centre and conducting a monthly discussion forum. In addition, FPDB members have also involved in advocacy and public campaign activities, which are targeted to amplify the struggle of PWD for social justice and equality. Other than these activities, this organisation has provided the participants with a vibrant gathering place where they like to congregate and engage in interactive discussions, almost on a daily basis. It is through all of these activities that many of the participants reported their experience of personal development.

Drawing on the data analysis, I identified four mechanisms through which the participants have been enabled to experience their involvement in FPDB as an empowering process by providing them with opportunities to accumulate knowledge and practical skills. These four mechanisms are:

- Becoming a source of knowledge and information.
- Developing practical skills.
- Expanding networks.
- Promoting personal growth.

The discussions that now follow explain in detailed each of these mechanisms and discuss how each mechanism has contributed positively to the participants' individual empowerment.

#### **7.3.1. Becoming a source of knowledge and information.**

In reflecting the benefits of joining FPDB, the majority of the participants commonly reported that this organisation has expanded and updated their knowledge on various social issues including those that are particularly related to disability. The participants' reflections

indicate that FPDB appears to provide them with the opportunities to broaden their knowledge by functioning as a pool of information:

There are so many benefits of joining FPDB. If I just stay home, most likely I will just be busy with my gadget, so won't get the same kind of conversations I have in FPDB. I have gained more knowledge, no matter good knowledge or bad knowledge; still it makes me having more knowledge. The conversations that I have here, I can use as a useful reference. If I just stay home, my knowledge will be limited to what I can get from television, Smartphone or Internet. But here, I can have live discussions ... more detailed ... I can find solutions here. After all, it's always better to talk in persons (Bagas, male, FPDB member).

There are many benefits. I can meet all these people and learn new ways of thinking, and most importantly I find a good match for playing chess. It is a good place for socialising (Wisnu, male, FPDB member).

I got all this information about training programs, also health insurances specifically targeted for *difabel* people. And the other day, I got information about how to apply for driving license for *difabel* people. Yes, that kind of information (Pawestri, female, FPDB member).

At least, now I know what I should do if I like to help *difabel* persons in my neighbourhood to access health insurance when they are getting sick. It is useful information. So, it's been a good experience (Gendis, female, FPDB member).

The quotations above suggest how joining FPDB has provided the participants with relevant information, ranging from general knowledge to specific advice. In the Indonesian context, where PWD have experienced on-going social exclusion and accessible sources of information are still a rarity, this organisation has been experienced as a useful resource for the participants to expand and update their knowledge. In this regard, FPDB as an empowering setting has created social connections that can function as a shared resource for accessing relevant knowledge and information. Such knowledge and information is a crucial entry point for acquiring various other meaningful accomplishments, such as knowing how to apply for a driving licence or how to register for health insurance.

Based on the observation during the fieldwork, I learned that accessing basic public services such as obtaining a driving licence or securing a government sponsored health insurance membership was not a simple process for the participants. For example, to secure a government-sponsored health insurance, the participants often have to go through several government institutions ranging from obtaining an endorsement letter from the village government up to getting approval from the health department at the District level. The process can sometimes be even more complicated as government institutions in Indonesia tend to operate with a complex bureaucratisation and a lack of professionalism. For instance, from the participants' experience I learned that the regulations and procedures for securing a government-sponsored health insurance membership are not always widely available and easily accessed. Such information is often available only through the Internet which not every FPDB member has access to. In addition, as nepotistic practices are still common in Indonesia, the participants reported that sometimes only PWD who happen to have familial connections with related government officials be the ones who can access such information.

Situated in this kind of socio-political context, it becomes apparent that the enabling feature of FPDB as a transformative setting is related to its function as an alternative source of

knowledge and information for the participants. In addition, such a context may further explain how the social connections in this organisation have functioned as a form of social capital for the participants, from which they can source practical supports for developing their personal capacities.

### **7.3.2. Developing practical skills.**

Another benefit that the participants associated with their involvement in FPDB is having the opportunities to develop their practical skills. The participants reported that through the social interactions and shared activities in this organisation, they have had chances to acquire managerial and working skills, which they did not have before. For instance, Luna found that participating in FPDB has provided her with an opportunity to learn organisational skills:

Now, I have more experiences about how to participate in an organisation, how to manage an organisation effectively, I have the knowledge for it now ... now I can see what are the challenges for developing an organisation with many people in it, how to manage the different opinions that people have, what strategy should be used to bring together different opinions (Luna, female, FPDB member).

Luna has lived with a disability since 2006 due to the injury sustained in the earthquake. She was in high school when the earthquake happened. FPDB is the first disability organisation that she joins to. She explained that before joining FPDB, she hardly participated in any social group. She was once invited to join a support group for PWD in her village, which was established following the earthquake. However, as a teenager, she was not interested to join the group because like many other support groups, which were established following the earthquake, the main activity in the group was providing financial loan for the

group members. Later on, she was introduced to FPDB by Agus (FPDB coordinator). For Luna, it was the regular gatherings and lively discussions in this organisation that drew her interest to participate. She said that she could not find such activities in the support group available in her village.

When I did the fieldwork, Luna was just joining this organisation for one year. During my regular visits to FPDB office, I had the opportunities to observe her active roles in facilitating the regular monthly meetings. During such meetings, she appeared to have confidence in articulating her views and opinions. Later on, through my conversations with the other participants who have known Luna since long before she joined FPDB, I learned that Luna's confidence and articulate public speaking have been emerging gradually as she becomes involved in this organisation. The other participants mentioned that before joining FPDB, Luna tended to be socially withdrawn.

Luna's experience illustrates how FPDB has provided the participants with shared activities (i.e., regular gatherings and lively discussions) that are rarely found in other disability organisations or support groups available in the Bantul District. It is through such activities that Luna has the opportunity to develop her practical skills, which in turn brings meaningful personal changes.

The role of FPDB as a medium for developing the participants' practical skills was also evident in Cahyo's experience. For Cahyo who works as a mechanic in the FPDB wheelchair service centre, he found that participating in this organisation has advanced his working skills:

I have more knowledge now ... yeah, more knowledge. Previously I could only repair bicycle, repairing bicycle was my profession, but then no one needs such a profession now. After I join FPDB, I can revive my profession by working at the service centre. Now I can repair wheelchairs, it gives me more advanced skills than just repairing

bicycles ...so, previously I just stayed at home, taking care of my chicken, now I can have fun working with wheels (Cahyo, male, FPDB member).

Drawing on the experiences of Luna and Cahyo, it becomes apparent how opportunities to accumulate knowledge and practical skills have played an important role in defining FPDB as an empowering setting. In line with previous studies on empowering settings (Balcazar et al., 2012; Langhout, 2012; Maton, 2008; Maton & Brodsky, 2011; Silva & Langhout, 2015), the participants' experiences indicate that skills development has functioned as instrumental mediators through which this organisation has been experienced as an enabling social environment. Furthermore, the participants' reflections also suggest that the opportunities to advance their knowledge and practical skills have contributed positively to their individual sense of empowerment (Seidman & Tseng, 2011).

### **7.3.3. Expanding networks.**

Another route for personal development found in FPDB is through the opportunities to expand the participants' networks. The participants' reflections indicate that they value their involvement in FPDB for it has widened their social connections.

Friends here, they have many links, many connections with other NGOs. I have come to know about all these NGOs from my friends here (Astuti, female, FPDB member).

Personally, I am a kind of person who likes to socialise. When I join FPDB, it is just great, so many benefits. I can work in other disability organisation, and that because I join FPDB. Now, I am regularly invited by friends from outside this district, and that's also because I hang out a lot with friends in FPDB (Amir, female, FPDB member).

As described by Astuti and Amir, FPDB has often been invited to participate in activities, which are organised by other disability organisations in Yogyakarta, such as attending a training program or joining public campaign activities. During my fieldwork, I observed that such invitations were always shared in the monthly meetings to decide who would attend the event. With such a mechanism, the opportunities to be involved in related activities outside FPDB were equally distributed among its members.

In this sense, the enabling feature of FPDB is indicated by its role in creating equal opportunities for the participants to expand their network. Such opportunities have become a crucial springboard for creating various other possibilities, including employment opportunities. How participation in this organisation has promoted job opportunities is discussed further in the next sub-category (i.e., *promoting economic independence*)

#### **7.3.4. Promoting personal growth.**

The participants reported that through their involvement in FPDB, they have experienced positive changes in some aspects of their personality, such as becoming more open and less temperamental. In this regard, this organisation appears to facilitate the development of the participants' personal capacities by promoting their personal growth:

Before joining FPDB, I just knew people in my neighbourhood. I didn't know that there are many *difabel* friends, out there. The only disability organisation I knew is PPDI, the one sponsored by the government ... so, yes, I admit that I used to be a narrow-minded person. But that was before I joined [FPDB] ... it [FPDB] made me realise that there are these friends who are caring for me, and it eventually grows my care for these friends too (Amir, male, FPDB member).



I'll put it this way, with this Internet thing, nowadays you can stay at home and you know everything out there, but that will be a narrow world, our real world will be still a narrow one. You may know everything via the virtual world but we will still need to have a real atmosphere, right? It [participating in FPDB] is particularly good for my emotion. Makes me less moody (Bagas, male, FPDB member).

The two quotations above indicate that the participants valued their involvement in this organisation not only for the opportunities to gain practical knowledge and skills, but also for it helps them improving their personal qualities. Such a personal growth was also evident in Puan's reflection. Puan is one of the members who are non-disabled.

There are so many eye opening life lessons that I learn from friends here. I learn a lot from all of them. Learning about their struggle, it helps me to put my own issues on perspective ... they [*difabel* friends] are dealing with complex challenges ... so when I am having a hard time, they give me strength. These friends are facing more difficult situations and they can make it, my difficulty is nothing, so I have to be able to deal with it. So, that is how I am thinking about it (Puan, female, FPDB secretary).

Puan's reflection suggests how participating in this organisation has enabled her to develop positive view on PWD. Instead of viewing PWD as helpless objects of pity (which is still a common practice in Indonesia), her interactions with PWD in FPDB have enabled her to learn the struggle of PWD as determined and competent activists.

The role of growth and mastery experience as defining features of empowering settings have also been reported in other studies (e.g., Balcazar et al., 2012; Maton & Salem, 1995; Maton & Brodsky, 2011, Silva & Langhout, 2015). These studies suggest that across different types of empowering settings, the presence of opportunities for capacity building has

been identified as an instrumental mediator for creating a transformative social site. In line with these studies, the participants' reflections indicate that opportunities to accumulate knowledge and practical skills that are available in this organisation have played a crucial role in defining FPDB as an empowering setting. This organisation has been experienced as an enabling social environment by functioning as a resource centre whereby the participants can have opportunities for developing and expressing a sense of personal efficacy as well as actual competencies.

#### **7.4. Promoting Economic Independence**

In addition to fostering emancipatory relationships and facilitating capacity building, FPDB has also been positively valued by the participants for its capacity to promote their economic independence. In reflecting their experience in this organisation, the participants placed particular emphasis on the role of FPDB in helping them addressing their economic struggle.

As discussed in chapter 3 (Contextualising the Study), PWD in Indonesia have been generally 30% to 50 % more likely to live in poverty than non-disabled people (Adioetomo et al., 2014). Like PWD in many parts of the world, the oppressive realities commonly experienced by PWD in Indonesia have often been reproduced and exacerbated by their unemployment and poverty (McDonald et al., 2007). The experience of FPDB members is not an exception. Through my observation during the fieldwork, I learned that FPDB members are generally self-employed in home-based micro businesses (i.e., traditional food seller, tailor, electrician), which hardly generate steady and adequate income for them and their family. Furthermore, their chances to get a professional role or position were very limited as pervasive discriminative practices toward PWD are still common in the Indonesian working environment.

In relation to their economic struggle, the participants' reflections indicate that they positively value their participation in FPDB for it creates a space where they can discuss as well as act upon their shared concerns and goals for having sustainable livelihoods. Drawing on such reflections, I develop *promoting economic independence* as the third sub-category that characterises FPDB as a transformative incubator. This sub-category captures the participants' reflections, which particularly reflect how they envisioned FPDB as a vehicle for achieving economic independence. There are three points of reflection identified under this sub-category, including:

- Economic independence as a powerful springboard.
- Creating job opportunities.
- Economic independence as a key to equality.

I detail each of these points in the following sections.

#### **7.4.1. Economic independence as a powerful springboard.**

In regard to their economic struggle, the participants appeared to have a shared belief that achieving economic independence is the first and foremost issue they need to address in order to have meaningful inclusion in their society. They seemed to view that economic independence is a determining entry point for achieving equality, dignity and autonomy:

The very first issue needs to be addressed is economic development ... you may have this new accessible crossing bridge being built, but if all friends here are still economically disadvantaged, why would we need to walk across the street as we have no money to buy anything from the shops (Ilham, male, FPDB coordinator).

The quotation from Ilham above captures the gist of *economic independence as a powerful springboard* as the first point of reflection that comes under the sub-category of

*promoting economic independence*. This point portrays the participants' emphasis on the crucial role of becoming economically independent. Like Ilham, the other participants also viewed that achieving economic independence is of paramount importance to them:

Hoping of having accessible environments or expecting that the government will show more commitment, that will be very difficult. Forget about that. I think what is more important is to find ways so that we can be economically independent. We won't be bothered of not getting health insurance from the government, when we are able to pay the costs by ourselves. We will be able to pay our own insurance if we can get a regular income from what we are doing at the wheelchair service centre ... Also the other day, Ilham has an idea for us to start vintage furniture business. So, if all these things work well, we can be a donor agency, like KARINAKAS (Puan, female, FPDB secretary).

The two quotations above suggest how pivotal the issue of economic independence is for the participants. As the likelihood for having structural changes seemed so vague, they considered that achieving economic independence would be a powerful springboard for alleviating their disadvantages. In this regard, the significance of FPDB as an enabling setting is related to the opportunities that the participants have to develop an alliance with those they share similar economic concerns and struggle.

When I asked the participants about their future dreams for FPDB, the participants mentioned that they wanted to see this organisation becoming more successful in promoting the economic independence of its members.

My future dream for FPDB is that we can do more to empower all friends here who not yet have a steady job. The other day, I talked to Ilham about the possibility of

expanding the services we offer at the wheelchair service centre, so that more friends can have a job from it (Amir, male, FPDB member).

I hope FPDB can sustain in the future, continue to be a forum for people to socialise, but also can create business opportunities for all friends here, can help them to have a job and be financially independent. Like that. So perhaps, we can be a social organisation but with a business unit to improve our economic life (Wisnu, male, FPDB member).

In short, we can have a prosperous life, but we should start by freeing ourselves from the stigma which views *difabel* people are dependent people ... so, first of all we need to be economically independent (Puan, female, FPDB secretary).

The quotations above highlight the participants' shared dream of making FPDB as an enabling catalyst for promoting economic independence. The participants appeared to share a similar view that becoming economically independent is a key to creating an accessible social environment. Similar to Werner's (1995) argument, accessibility for the participants is not merely about the technical issues of installing ramps or elevators but more importantly accessibility is about having sustainable livelihoods. In this sense, FPDB has enacted its empowering function by transforming the participants' individual economic struggle into a collective endeavour for achieving economic independence. Joining FPDB has allowed the participants to nurture and strengthen a shared belief that becoming economically independent is a determining starting point to advance their struggle for meaningful inclusions.

#### **7.4.2. Creating job opportunities.**

Currently, the shared dream of making FPDB as a catalyst for promoting economic independence has been manifested through the wheelchair service center. The service center has provided job opportunities for five members who are hired as the mechanic and administration staff. For these members, participating in FPDB has directly benefited them by providing a job opportunity:

It is great to join FPDB, really great. I can go out, be here and there. I can have a job, the income is not much but it is enough to make a living (Cahyo, male, FPDB member).

There are many benefits of joining FPDB, first I have more friends now. Before I join FPDB, my social circle was very limited, but now I can be a friend with all of these people. If I do not join FPDB, I may never know them... also through the wheelchair service centre, I can have a job of making the pillow seats ... it gives me additional income (Narto, male, FPDB member).

Currently not all of FPDB members can have a job opportunity through the wheelchair service centre. Furthermore, not all of the members have skills, which are particularly relevant for working at the wheelchair service centre. Therefore, there has been a shared concern among FPDB members to be able to create more jobs and business opportunities. It is such a situation that has motivated FPDB members to continuously explore business ideas and possibilities, which will enable them to be a successful entrepreneur. Through my observation during the fieldwork, I learned that the participants often used the daily informal gathering in the FPDB office to share business ideas or to learn from one another about tips and strategies of starting and managing a business.

By creating employment opportunities, this organisation has a potential to improve the living condition of the participants. In this regard, the transformative feature of FPDB is related to its ability to attend to the material context of the participants' oppression. Such a feature is crucial, considering that poverty has become a pressing challenge for majority of PWD (Adioetemo et al., 2014; Yulianto, 2015). The participants' reflections suggest how this organisation has functioned as a resource centre that enables them to have or explore job opportunities.

#### **7.4.3. Economic independence as a key to equality.**

The participants' reflections suggest that achieving economic independence has more complex meanings beyond a matter of being able to survive financially. They appeared to share a belief that economic independence is a key to equality.

When we are able to be economically independent by doing well in our work, people in our society will see us differently. They will no longer see our impairment (Ilham, male, FPDB coordinator).

My dream is simple, to see friends here no longer being dependent to others. That's all. It means that they need to have adequate income. If they have adequate income, people in our society will certainly show more respect and be more willing to listen to our voices (Agus, male, FPDB coordinator).

These quotations from Ilham and Agus underline the powerful meanings of being economically independent for the participants. In this sense, by creating job opportunities, FPDB does not merely function as a vehicle for obtaining sustainable livelihoods. Rather, in

line with Maton's (2008) argument, this organisation has functioned as an empowering setting by enabling its members to exercise their self-determination and to have greater control over their lives. Such a sense of determination is of paramount importance for the participants considering the issue of employment has often become the site where their marginalisation is reproduced and exacerbated.

As reported by Adioetomo et al. (2014), self-employment is the most common mean of living for majority of PWD in Indonesia because PWD are still generally discriminated in other types of working environment. In addition, PWD tend to have limited options for self-employment because they rarely have the opportunities to attain formal educations or training programs that meet their talent and interest. Instead of addressing the interest and talents of PWD, the types of training programs available for them are often reinforcing the existing prejudicial attitudes toward PWD. Suharto (2011), a prominent disability activist in Indonesia stated that, "providing employment for diffabled people remains focused on menial jobs rather than jobs that use the intellect" (p. 37). Such discrimination seems to be underpinned by a prejudicial view that portrays PWD as inherently incompetent individuals. This point was reflected in Amir's experience when he shared about his disappointment with a training program organised by a government institution:

I was once invited to attend a training program on animal husbandry. I was told that after the training I would be provided with some hens and an egg incubator machine. But when I received the machine, it did not work, and instead of getting some hens, they gave me six roosters. How on earth, I would be able to start a chicken farm with six roosters? That's the point where I started to think that I was just an object for them, an object for training programs. As the assistance that they provided did not meet our needs, we could not utilise their assistance (Amir, male, FPDB member).



Amir's reflection implies the complex and powerful meanings of becoming economically independent for the participants. Drawing on Amir's reflection, it becomes apparent that the participants' conscientious efforts to achieve economic independence can be considered as a form of resistance toward the common patronising practices in Indonesia which position PWD as incompetent individuals. In this regard, FPDB has functioned as an empowering setting by enabling the participants to consolidate their shared vision and endeavour for achieving economic independence through which they can restore and assert their self-determination as well as their sense of agency.

## **7.5. Chapter Summary**

Key findings from this current study suggest that FPDB has functioned as an enabling social environment for the participants as it creates opportunities for acquiring a set of knowledge and skills essential for addressing their socio-economic marginalisation. Through such opportunities, the participants have been enabled to experience their involvement in this organisation as a transformative journey.

The findings of this study further suggest the presence of three psychosocial processes that have overtime enabled the participants to experience their involvement in FPDB as a transformative activity. These three processes include: (a) fostering emancipatory relationships, (b) facilitating capacity building, and (c) promoting economic independence. Through these three processes, FPDB has functioned as accessible resource centre for the participants by providing opportunities for developing social connections, personal and collective capacities, as well as improving their material living conditions.

Furthermore, FPDB has functioned as an enabling social environment by restoring and validating the participants' self-determination and a sense of agency. The participants' reflections suggest that the ability to assert their self-determination and a sense of agency is

central for igniting their personal and collective resistance against the socio-economic marginalisation commonly imposed upon them.

As a social setting, FPDB is embedded within the broader social ecology of community life in Javanese rural villages. Situated in such a context, the participants' reflections suggest that the significance of this organisation as an enabling social environment centres on its ability to promote transformative social processes, which speak to the particular historical, cultural and political challenges that have characterised the participants' local community.

## Chapter 8

### FPDB as a Mindset Changer

#### 8.1. Introduction

*FPDB as a mindset changer* is the second overarching conceptual category that represents the overall findings of this current study. While the previous conceptual category (i.e., *FPDB as a transformative incubator*) focuses on the empowering processes and practices that have characterised FPDB as an enabling social setting, this second conceptual category is particularly concerned with the empowering outcomes that are experienced by the participants as a result of their active involvement in this organisation.

Figure 4 presents the structure of this conceptual category along with its constituent sub-categories and attributes. Guided by this figure, I start this chapter by discussing the overall meaning of *FPDB as a mindset changer*. Next, I examine each sub-category and how this contributes to the development of this organisation as an empowering setting.

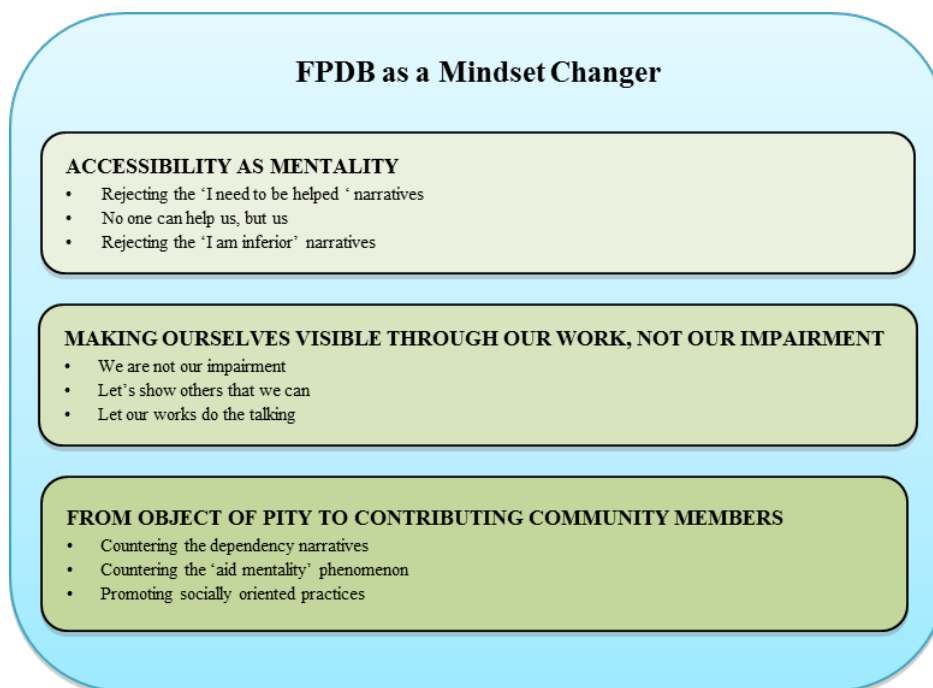


Figure 4. Second Conceptual Category: FPDB as a Mindset Changer

*FPDB as a mindset changer* refers to the findings of this study, which suggest how this organisation has enabled the participants to alter their mindset, with particular regard to how they give meaning and respond to their disability. The participants reported that their involvement in FPDB has shifted their way of thinking. Previously, they tended to view disability as a form of personal inferiority. Through their participation in this organisation, they gained an understanding of disability as a socially constructed problem.

Based on the data analysis, I identified that FPDB has transformed the participants' understanding of, and responses to, disability through two mechanisms. Firstly, this organisation has enabled the participants to undo the internalisation of negative stereotypes commonly imposed upon PWD in Indonesia. In other words, this organisation has become a space where the participants can invalidate the dominant deficit-oriented representations of disability. Secondly, the findings of this current study suggest that by being actively involved in this organisation, the participants are able to proactively create alternative understandings and meanings of disability that promote enabling mindsets and actions. Informed by these alternative understandings and meanings, they were able to re-conceptualise their personal and collective identity in ways that reflect and amplify their resistance against discriminatory systems and practices.

For instance, the following quotation from Luna illustrates how participating in FPDB has enabled her to reject the negative stereotypes commonly associated with disability. She explained:

I believe that to live a life is to bring goodness for others around us. Before joining FPDB, all that I knew was that I was a burden to other people. But now my mindsets have changed. Although I have limitations, I want to be able to help other people around me. I am still in a learning process, but I want to make sure that I can bring goodness for others around me (Luna, female, FPDB member).

Similar to Luna, the other participants recurrently highlighted how their active involvement in FPDB has transformed the way they give meanings and respond to disability. The participants' reflections suggest that their mindset changes have occurred gradually as they engage in social interactions that are nurtured in this organisation. Through these interactions, they are able to create and share symbolic resources (i.e., conversations, stories and metaphors), which allow them to understand disability as a socially constructed problem. Such understandings have in turn enabled the participants to recognise socio-cultural practices that have produced and sustained their marginalisation, particularly in regard to how disability has been predominantly portrayed as a form of personal inferiority.

Drawing on such findings, I therefore borrow some concepts used in the literature about narrative approaches to empowerment (e.g., dominant narratives, alternative narratives), in order to describe the participants' experiences more accurately (e.g., Rappaport, 1995, 2000; Salem, 2011). As argued by Rappaport (1995), using narrative approaches to empowerment allows researchers to examine how particular narratives are used to maintain privileges and to rationalise the marginalisation of certain groups or individuals in society. In addition, such approaches also create possibilities for exploring ways through which marginalised individuals or groups can question, disrupt and contest the reproduction of hegemonic narratives that underpin their oppression (Case & Hunter, 2012; Rappaport, 1995, 2000, 2011; Salem, 2011)

I utilise narrative perspectives to present the findings as how the participants gave meanings to FPDB reflects the way they have positioned themselves in relation to the dominant narratives of disability in the Indonesian socio-political and cultural context. As reflected in the way it is generally talked about and addressed, disability in Indonesia is still predominantly narrated as a form of individual deficiency or abnormality (Adioetomo et al.,

2014; Suharto, 2016). Situated in such a context, it is necessary to understand the meanings and significance of how this organisation has enabled the participants to question, disrupt, challenge and alter the dominant narratives of disability that have produced and sustained their marginalisation.

Drawing on the data analysis, I identified three sub-categories that describe the strategies developed by the participants to transform their understandings of disability and to cultivate empowering personal and collective identity. These three sub-categories are:

1. Accessibility as mentality.
2. Making ourselves visible through our work, not our impairment.
3. From object of pity to contributing community member.

The following sections detail how each of these sub-categories speaks of the way FPDB has been experienced as a mindset changer by the participants.

## **8.2. Accessibility as Mentality**

*Accessibility as mentality* explains a set of attitudes promoted in FPDB that has enabled the participants to reject the internalisation of the dominant deficit-oriented narratives of disability. The participants' reflections suggest that rejecting the internalisation of oppressive narratives of disability is the first act of resistance that needs to be developed in order to achieve their aspirations for meaningful inclusion. The majority of the participants explained that they needed to tackle what they identified as the 'problematic mentalities' of PWD before attempting to change the external circumstances that have produced their oppression.

Drawing on the participants' reflections, the phrase 'problematic mentalities' refers to a range of disabling psychosocial issues commonly experienced by PWD as a result of internalising the oppressive narratives of disability. These issues include shame, a sense of

inferiority, the feeling of not deserving. The participants viewed that addressing these psychosocial issues is crucial to counter the normalisation of oppression of PWD. In this regard, *accessibility as mentality* refers to the participants' comments that their liberation is dependent upon their willingness and courage to tackle their own disempowering mentalities. The following excerpt from Ilham captures the gist of this sub-category:

Yes, mentality. The mentality of the *difabel* people themselves ... Let's not start with demanding others to change how they treat us. Don't demand others to change; we should start by looking into ourselves and finding our strengths, potency that we can develop. Accessibility is something that will follow when *difabel* people are present and actively involved in their environment. Accessibility is not only talking about physical infrastructure. Let's say, there is a *difabel* person who regularly goes to a market and there is an area with a tilted floor in the market. I am sure the regular presence of a *difabel* person in this market will encourage people to start thinking of doing something with the tilted floor so the *difabel* person can access the area ... so accessibility is something that will happen when we are actively involved in a particular place, ... [when] we have willingness and courage to go out (Ilham, male, FPDB coordinator).

Similar to Ilham, the other participants generally viewed that transforming their disempowering mentalities into positive mindsets was the determining entry point for achieving their liberation from discrimination and marginalisation. Drawing on the data analysis, I identified three strategies used by the participants to undo the internalisation of disempowering mentalities commonly imposed upon them. These three strategies become the attributes that characterise the sub-category of *accessibility as mentality*, and these include:

- Rejecting the ‘I need to be helped’ narratives.
- No one can help us but us.
- Rejecting the ‘I am inferior’ narratives.

The discussions that now follow explain in detailed each of these strategies and how it contributes to transform the participants’ mindsets and attitudes.

### **8.2.1. Rejecting the ‘I need to be helped’ narratives.**

*Rejecting the ‘I need to be helped’ narratives* represents the participants’ resistance against the dominant portrayal of PWD as helpless individuals who need to be saved, rehabilitated or normalised by non-disabled people. In the Indonesian context, this kind of portrayal has been commonly manifested and reproduced through various social practices, which position PWD as weak or inherently vulnerable individuals. For instance, these portrayals have been perpetuated through the proliferation of charity-based intervention programs for disability (Adioetomo et al., 2014).

As structural and systemic interventions to disability are still a rarity, PWD in Indonesia are generally conditioned to rely on donation to be able to make a living. The opportunities for PWD to have professional employments are so scarce. Such a situation has eventually created a normalised patronising narrative of PWD as helpless individuals (Adioetomo et al, 2014; Yulianto, 2015). In addition, such social practices have also reinforced the view of disability as a personal tragedy and pushed aside the understanding of disability as a form of social oppression (Suharto, 2011; Thohari, 2007).

In the case of local communities in the Bantul District, this tendency to portray PWD as helpless individuals has been complicated by the particular situation that emerged during the post disaster period. Following the earthquake, local communities in Bantul had become a working site for a large number of humanitarian and aid agencies (Joakim, 2013; Zaumseil et



al., 2014a). The presence of agencies offering support was crucial for recovering the local communities. However, my observation during the fieldwork suggested that the presence of these humanitarian and aid agencies had also raised a concern among the participants about the possibility of PWD in Bantul becoming dependent to others' help and neglecting their own collective capacities to overcome their difficulties.

Situated in such a context, *rejecting the 'I need to be helped' narratives* represent an alternative framework promoted in FPDB to counter the pejorative representations of PWD as helpless individuals. In other words, this concept reflects the role of this organisation as a setting that has enabled the participants to recognise how they may have unintentionally contributed in reproducing their oppression by internalising the patronising portrayal of PWD.

Addressing the internalisation of subjugating narratives of disability has become a shared concern among the participants, as it was evident in Agus's reflection when he explained his motivation to initiate this organisation:

The first time I met some of these friends was sometimes after the earthquake. When I met them [friends who have become disabled because of the earthquake], they were always just whinging and whinging. They thought that their situation was the worst. Even when they had a chance to meet friends who have been living with disability long before the earthquake, they still thought that their situation was worse ... It means there was an issue with self acceptance, and I thought that issue needed to be addressed first (Agus, male, FPDB coordinator).

Ilham shared a similar view when he recalled what motivated him to initiate FPDB along with Agus and some other early members of this organisation:

Back then, when I gathered with some of these friends, some of them were mainly talking about aid, aid, and aid. Would they be dependent to aid for the rest of their

life? That was when I started to feel, I feel that we would not develop ourselves if we always kept that way of thinking (Ilham, male, FPDB coordinator).

Internalised oppression as a common psychological challenge among PWD has been discussed in a number of studies (e.g., Goodley, 2011; Oliver, 2009; Reeve, 2006). Consistent with these studies, the quotations from Ilham and Agus above illustrate how dealing with such a psychological challenge has also become a shared concern among FPDB members. Their reflections suggest that without firstly tackling their internalised oppression, any further attempt to overcome their marginalisation may become more difficult. The participants' attempt to unpack their internalised oppression has been manifested in their willingness to recognise, question and alter their own disabling mindsets and attitudes. Ilham illustrated such a process in this following quotation:

The most important thing is our mentality. When we started this organisation, we always said this to our friends, “no matter how much money people will give you, thousands or even billions, when we are still in that ‘begging for help’ mentality’, asking people to take care of us, being dependent to other people, to the government; it will be impossible for us to make a progress. Although, we may only have one or two dollar, but when we have that ‘how can I develop what I have’ way of thinking; we can be successful (Ilham, male, FPDB coordinator).

Ilham's reflection resonates with the literature, which highlight the role of conscientisation in facilitating psychological empowerment (e.g., Campbell & Jovchelovitch, 2000; Kagan & Burton, 2010; Prilleltensky, 2008). Grounded in the work of Paulo Freire (1996), conscientisation refers to a process by which marginalised groups or individuals gain critical awareness and understanding of the social forces that shape their oppressive realities

and their ability to transform their living conditions. Unpacking the internalisation of oppression is a crucial part of conscientisation (Freire, 1996; Freire & Macedo, 1998). This process encourages marginalised individuals to recognise how they may have unintentionally contributed in sustaining their own disadvantages by internalising disempowering mindsets and attitudes commonly imposed upon them. Attaining this kind of awareness has often functioned as a springboard for developing personal and collective acts of resistance (Kagan & Burton, 2010; Prilleltensky, 2008). In this sense, Ilham's reflection suggest that FPDB has functioned as an empowering setting by promoting the process of conscientisation that enables the participants to undo the internalisation of oppressive narratives of disability.

A reflection from another participant suggests that countering the internalisation of oppressive narratives on disability requires courage and determination to break away from the patronising practices that have become a general pattern in how PWD in Indonesia are treated. Puan illustrated this point when she explained why some of the early members of FPDB eventually left this organisation:

I think they don't want to step out from their comfort zone. They seem comfortable with their current situation. They don't want to have critical views because it may bring consequences. For them, the department of social affairs is their mother and father, they don't want to challenge the department of social affairs because they are afraid of not getting any more help (Puan, female, FPDB secretary).

Puan's reflection suggests that *rejecting the 'I need to be helped' narratives* involves a process of challenging the patronising approach commonly used by related government institutions or authorities to address the issues of disability. Her reflection highlights the risk that may come with the choice of resisting the oppressive narratives on disability. Such a resistance appears to involve a complex process, as it requires the participants to confront

institutionalised practices that have perpetuated patronising narratives of disability. Situated in the particular context of Javanese culture, Puan's reflection also suggests that resisting the patronising narratives of disability may involve a process of negotiating with the 'parent-children' hierarchy commonly used by authority figures to relate with commoners (Shiraishi, 1997).

### **8.2.2. No one can help us, but us.**

In reflecting their personal and collective attempts to counter the dominant oppressive narratives on disability, the participants frequently highlighted the determining role of one's personal will or motivation as the driving force of their collective resistance:

You may tell someone that joining FPDB will make him grow, you may think of encouraging this person, but if he himself doesn't have willingness, what you say about FPDB will be just meaningless (Jatmiko, male, FPDB member).

We can have all those advocacy things being done, but if the PWD themselves are not active, all of those efforts will be useless, I reckon (Ilham, male, FPDB coordinator).

The two quotations above illustrate a common view shared among the participants, that is, the view that emphasises the responsibility of the PWD themselves to initiate and advocate their resistance against oppressive narratives commonly imposed upon them. Drawing on such reflections, *no one can help us, but us* represents the participants' shared belief that they are responsible for their 'fate'. In this sense, the enabling feature of FPDB as an empowering setting is related to its ability to raise the participants' awareness of their own agency in determining the course of their transformation. Such awareness is reflected in the

participants' accounts when they shared what they identified as the key factors of their collective struggle:

For me, the key factor is to make sure that we have come to terms with our personal issues. Like, with some friends who become disabled because of the earthquake, no matter how many billions aid would be given to them, when they had not come to terms with their personal issues, it would not make any good. But, if they had come to terms with their personal issues, you might just give them a small amount of aid, but they would make a progress (Agus, male, FPDB coordinator).

When I asked Agus further about what he meant with personal issues, he described:

Something like having low self esteem, being dependent to others, but mostly having low self esteem. Back then after the earthquake there were many organisations providing aid. But at that time, some friends had not come to terms with their personal issues. So, no matter how much they received aid, they did not make any progress. For the organisations, they might think they had done a successful project by ensuring that their aid had been distributed, but their aid did not bring many changes.

Ilham shared a similar reflection with Agus. For Ilham, in order to change the predominantly deficit-oriented narratives of disability, PWD should start by firstly changing their way of thinking:

When PWD do nothing but demanding others to make a change or merely complaining of not getting assistance, I think that kind of attitude will just weaken our position, and it may even trigger conflicts between us, why that person is getting assistance and I am not. I think it will be different if we start by looking into

ourselves, talking to ourselves, what sort of capacities that we have, what can I do for myself, my family and my community (Ilham, male, FPDB coordinator).

The quotations from Ilham and Agus above reflect how this organisation has enabled the participants to foster their sense of agency. In line with Cleaver's (2007) argument, the participants' sense of agency refers to a belief that they have capacity to change their challenging living conditions (Cleaver, 2007). Such a finding is consistent with previous authors, which theorise the link between conscientisation and the development of people's agency (e.g., Campbell & Jovchelovitch, 2000; Kagan & Burton, 2010; Prilleltensky, 2008). By enabling the participants to unpack their disabling mindset and attitudes, FPDB has helped the participants to gain more confidence in their ability to tackle their marginalisation.

The participants' reflections further suggest that by emphasising their agency, it does not mean that the participants have ignored the role of societal factors in producing their oppression. Rather, this emphasis on the role of their own agency seems to emerge from the awareness that prioritising structural changes appears to be less feasible in the current social-political context of Indonesia:

Some organisations tend to be busy with targeting upper level changes, like demanding regulations on disability, but often a regulation is just a regulation. For example, now we have the regulation on inclusive education that demands schools to accommodate children with special needs, but it is just a regulation, right? Factually, not every school implements the regulation (Tulus, female, FPDB member).

We may have a village-based regulation on disability and some people may think that having such a regulation is a success story. But let say, you may then do a survey and ask everyone in the village, I don't think many of them will know about the

regulation, they don't care with such a thing. So, it is back to the *difabel* people themselves. Talking about the participation of *difabel* people in society, it will only happen when the *difabel* people are willing to participate (Ilham, male, FPDB coordinator).

Drawing on the two quotations above, it can be inferred that the participants' emphasis on the role of their own agency reflects a proactive response to the unfeasibility of relying on legal and political interventions to address disability issues in the Indonesian context. Such limitations were evident in the way local governments that were involved in the implementation of the CBR program responded to the issues of disability.

As explained in chapter 4 (the profile of FPDB), the emergence of FPDB as a formal disability organisation was facilitated by KARINAKAS, a non-government agency, which initiated a CBR program in partnership with a number of villages in the Bantul District. Considering this background, therefore, my data collection included a process of obtaining archival data from the related local governments in order to have a broader picture of how the issues of disability had been generally approached in the local communities where FPDB members come from.

During the data collection process I learned that one of the villages already had a village-based disability act. It is an exceptional achievement for a village in Indonesia to have a legal regulation on disability considering that structural and political interventions to disability are still a rarity. Therefore, I was so eager to obtain the copy of the act when I heard that one of the villages, which were involved in the CBR program, had legalised its own disability act. However, when I met the Social Affairs Officer in the village, he explained that he could not provide either the hard or soft copy of the act because the file was missing from

the village's storage archive. My further attempts to get the copy of the Act were fruitless as no one in the village office had a copy of it, not even the head of the village.

This particular experience had prompted me to question the extent to which local governments in these local communities had a political will to conscientiously address disability as a community-based issue. This situation also helped me to understand why advocating structural changes (e.g., demanding legal enforcement to tackle discriminatory practices) tends to be less emphasised in FPDB. While acknowledging the importance of structural interventions to tackle their disadvantages, the participants' reflections suggest that possibilities for advocating such interventions are very limited due to the Indonesian government's lack of political commitment to fulfil the rights of PWD. As a result, FPDB tends to focus on addressing the socio-psychological and economic challenges experienced by its members (e.g., overcoming disabling mentality, promoting sustainable livelihoods).

Such a finding underlines the need to understand empowerment as a relational and situated praxis (Christens, 2012; Kesby, 2005; Rappaport, 1987; Riger, 1993). A different context implies different challenges and possibilities of empowerment. In this sense, FPDB has functioned as an empowering setting by enabling the participants to proactively develop transformative practices, which are responsive to their larger cultural, historical and political settings.

### **8.2.3. Rejecting the 'I am inferior' narratives.**

Another form of oppressive narratives on disability, which has been commonly experienced by the participants, is the portrayal of PWD as inferior individuals. As a result, like many PWD in Indonesia, the participants have been conditioned to look down on themselves and burdened by disabling psychological issues such as a sense of shame, lacking a sense of worth or feeling of not deserving to be treated equally. In the Indonesian context,



such psychological challenges often become more complicated for it is still common to associate disability with stigmatising views of ‘being punished by God’ or ‘paying for bad karma’ (Thohari, 2007)

Situated in such a context, *rejecting the ‘I am inferior narrative* represents the participants’ resistance to the internalisation of inferior identity as generally imposed upon them. *Rejecting the ‘I am inferior’ narratives* captures the participants’ reflections in which they identified the types of empowering mentalities that have been fostered in FPDB to disrupt the internalisation of subordinate labels and status. The participants’ reflections suggest that in order to resist the internalisation of their subordination, PWD are expected to have courage and determination to be socially active.

I think a community will have better awareness on disability issues when *difabel* people are actively involved in the community. For example, they actively participate in *gotong royong* [the tradition of doing community works regularly organised in Javanese villages], ... But if *difabel* people still think “Oh...I am just a *difabel* person, I will not be able to contribute anything” then the community’s awareness on disability issues will remain low, and people will keep thinking, “it’s okay that he is not joining *gotong royong*, he won’t be able to do much anyway” So, like that, people will have a pity on us and get us a dispensation, and in turn, we will always be regarded as the weak, and that’s all started with us not wanting to be active in our community (Ilham, male, FPDB coordinator).

In this quotation, Ilham reflected how PWD might contribute in reproducing their oppression. In addition, he suggested that the willingness of PWD to be socially active is a key to counter the perpetuation of subordination and inferiority. Astuti expressed a similar

view when she shared what she understood as the key challenge in advocating PWD's struggle for equal access and opportunities:

I think the challenge is not on the community but on the *difabel* people themselves. When we are willing to participate in our community, people in our community will be able to learn about our situation. But if we never go out, then people in our community will not pay attention to us ... and it is our choice to go out or not. I can try every possible way to motivate someone so that she is willing to go out, but if she chooses not to do so, then it is not going to happen ... because some friends still have low self-esteem, they have low self-confidence, "Oh... I am just an impaired person, why should I join with normal, healthy people". Like that, so, it should start with us having the willingness to go out (Astuti, female, FPDB member).

Amir, another participant, also viewed that PWD's willingness to be socially active is central to advance their struggle for meaningful inclusion in their community. While acknowledging that promoting an inclusive society requires structural changes in the community, he made a point about the need for PWD to change their attitude.

I think *difabel* people themselves need to change their attitude, we should have the courage to go out, to show others who we are, for example by joining social activities in our community ... I think from there, our community will be able to learn about our needs and issues. But I must admit it's not easy. It takes time to develop this kind of understanding, and it will not happen only through one or two persons, there should be a driving force from society or an organisation (Amir, male, FPDB member).

While highlighting the need for PWD to change their attitudes, Abas's reflection also suggests the social nature of such changes. His reflection underlines that fostering attitude

changes requires the presence of and interaction with others in an enabling social setting. In this sense, Abas's reflection suggests that FPDB has functioned as an empowering setting by creating social interactions that encourage the participants to change their attitudes toward the inferior narratives commonly imposed upon them. Through the social interactions that have occurred in this organisation, the participants are encouraged to develop enabling mentalities that may activate their resistance against the inferior labels and status commonly associated with disability.

In summary, the overall findings presented in this section are consistent with the argument, which views that addressing the socio-psychological aspects of oppression is as crucial as advocating structural changes to transform the oppressive realities commonly experienced by PWD (Blackmore & Hodgkins, 2012; Reeve, 2006; Thomas, 2014). As argued by Thomas (2014), any hope for resistance against disabling systems and practices, "lies in a disabled person's ability to reject and resist the medical and associated categories imposed upon them, that is, to break free from the discursive bonds by which they are tied" (p. 47).

### **8.3. Making Ourselves Visible through Our Works, not Our Impairment**

This sub-category represents another enabling strategy used by the participants to counter the oppressive narratives of disability. This sub-category is particularly related to the role of FPDB as a place where the participants can learn and work together. Through such opportunities, the participants have been enabled to foster empowering personal and collective identities, which are centred on their work and achievements. These empowering identities have in turn allowed them to counter the deficit-oriented narratives commonly imposed upon them. Ilham was one of the participants who shared this kind of view on this organisation:

What we try to develop in FPDB is a belief that we should make ourselves recognised through our works. This is a place where we can learn and work together. Let's develop ourselves together ... So, it is this kind of spirit that we try to promote here in FPDB (Ilham, male, FPDB Coordinator).

The participants' reflections indicate that by functioning as a place where they can learn and work together, FPDB is not only pragmatically meaningful (e.g., providing additional income source, creating job opportunities). This organisation appears to be also symbolically powerful. The participants suggested that having the opportunities to engage in productive activities have enabled them to place their works and achievements as the cornerstone of their personal and collective identities. The participants found that such identifications have afforded them a more empowering sense of self, which enable them to dismantle the predominantly deficit-oriented identities imposed upon PWD.

Drawing on the data analysis, I identified three strategies used by the participants to foster empowering personal and collective identities, which are focused on their capabilities, work and achievements. These three strategies are conceptualised as:

- We are not our impairment.
- Let's show others that we can.
- Let our works do the talking.

Each of these strategies is detailed in the following sections.

### **8.3.1. We are not our impairment.**

The concept of *we are not our impairment* represents two issues raised by the participants. Firstly, this concept captures the participants' reflections in which they shared their frequent negative experiences of being identified as impaired persons. Secondly, it

describes the participants' reflections which value FPDB as a social space where they can collectively counter the perpetuation of deficit-oriented identities imposed upon them.

The following excerpt from Ilham provides an illustration of how the pejorative identifications of PWD as impaired persons still become a common negative experience for the participants:

There are still staff at the department of social affair who call us impaired persons, yes, impaired persons, they call us that way. The fact that it is said by people who have been working for long time in this department, it obviously reflects their view on us. If someone is new in this department and he calls us impaired persons, we may assume that he has not known about this *difabel* term. But when those who have been working for long time in this department call us impaired persons, then you can tell that this department basically still views us as the weak. They don't see our potency (Ilham, male, FPDB coordinator).

Ilham's reflection particularly points to the tendency of related government institutions in Indonesia to still reproduce pathologising views on disability, despite current attempts of disability movements in Indonesia to counter such a view. In the last 10 years, there has been an attempt to disseminate the term *difabel* to identify PWD. *Difabel* is the preferred term in the Indonesian context to refer to PWD, which is considered of being more consistent with the social model of disability (Suharto, 2011; Suharto et al, 2016). Disability organisations in Indonesia, particularly those which adopt critical views on disability, have made conscientious efforts to popularise the term *difabel* as a counter to the predominantly degrading terms used to identify PWD (Fuad, 2011; Suharto et al., 2016; Yulianto, 2011).

Despite the attempts to disseminate the term *difabel*, the participants' reflection suggests that the use of impairment-focused labels to address PWD has not been completely

left behind. It was against such a backdrop that the participants appeared to value their involvement in this organisation as an opportunity to foster collective resistance against such a demeaning practice. Cahyo was one of the participants who valued his participation in FPDB for such a reason:

All of us are working sincerely to revive ourselves. Let's not make us as an object of ridicule to government officials. We are here to find ways for reviving ourselves, what we can do to resist the demeaning comments from government officials. As *difabel* we are often looked down. So, let's not make ourselves becoming dependent to others, no matter how we should stand on our own feet (Cahyo, male, FPDB member).

Similar with Ilham, Cahyo also pointed to how authority figures (i.e., government officials) may have contributed in perpetuating demeaning views on disability. In this sense, one of the challenges faced by the participants is to deal with those who have become the dominant power in perpetuating oppressive narratives on disability, through the reproduction of deficit-oriented labelling of PWD. The participants' experiences also suggest the significance of language as a symbolic arena where their marginalisation has been reproduced as well as challenged. In line with Mark's (1999) argument, the participants' comments show that disputing the degrading terminologies used to identify the personhood of PWD has become an important part of their resistance and liberation.

Dealing with the stigmatisation of PWD as damaged or defective persons has often been reported as a major aspect of experiencing disability as a form of social oppression (Gill, 2016; Harter et al., 2007). The findings of this study suggest that such stigmatisation has also become a common socio-psychological challenge for the participants. Therefore, the enabling feature of FPDB as an empowering setting is related to its ability to foster the participants' resistance against such stigmatisation. The participants' reflections suggest that through their

involvement in this organisation, they are able to reconceptualise their identity in ways that reject the deficit-oriented identifications imposed upon them. FPDB has enabled them to develop critical awareness on the dominant narrative of disability and how such narratives may have produced and sustained their marginalisation. As argued by some scholars (e.g., Balcazar et al., 2012; Case & Hunter, 2012; Rappaport, 1995; 2000), such an awareness is central for enabling marginalised individuals to resist their oppression, as this awareness may stimulate the development of empowering shared narratives.

### **8.3.2. Let's show others that we can.**

The concept of *let's show others that we can* explains the participants' collective spirit to challenge the oppressive narratives of disability by asserting themselves as competent individuals. This concept captures the participants' reflections, which view FPDB as a social space that has enabled them to represent themselves as socially active and aspiring community members. Such a representation is instrumental for enacting the aspiration of this organisation to develop its members as a role model for other PWD in their locality. Jatmiko who has become disabled because of the injury sustained in the earthquake illustrated this point:

From Agus who has been living with disability since he was young, I learn that as *difabel* persons we can grow and develop ourselves. He is my role model. He is very well known in our community, he has a vast knowledge, and so I can approach him and ask his opinions on something. Having conversations with him has expanded my perspectives on life (Jatmiko, male, FPDB member).

Jatmiko's reflection suggests that this organisation has provided him with opportunities to learn from a role model as well as to develop himself as a role model. Such

opportunities appear to be instrumental in promoting the participants' empowering identity. The participants' reflections indicate that being actively involved in FPDB is not only pragmatically meaningful (e.g., advancing their practical skills, expanding networks), but also is symbolically important. Participating in this organisation has created opportunities for them to demonstrate themselves as competent individuals. Such opportunities are pivotal because by asserting themselves as competent individuals, the participants have been enabled to invalidate the predominantly deficit-oriented portrayal of PWD. Amir illustrated this point when he recalled the involvement of this organisation in the Independence Day carnival in 2009:

We joined the Independence Day carnival with other groups in the community. Other than the Independence Day carnival, we also participated in *Takbiran* night [annual religious carnival to mark the end of *Ramadhan*, the fasting month for Muslim]. By participating in such events, we want to show our community of our existence. We want to promote an understanding that we do exist and we can do activities along with other groups in our community (Amir, male, FPDB member).

Amis' reflection suggests that FPDB has functioned as an empowering setting by enabling the participants to make their stories of resistance be known by others. Similar views were shared by Wisnu and Jatmiko: "FPDB is to help PWD to do something and not just stay home" (Wisnu, male, FPDB member), and "FPDB helps our community to be aware of our presence and that we can be part of our community ... that we have the same rights, that we are here and we are equal. I think that is the very aim of FPDB" (Jatmiko, male, FPDB member).

These quotations above illustrate the symbolic meanings that the participants ascribed to their shared activities in this organisation. Through their shared activities, the participants have been enabled to resist the normalised exclusion of PWD, which have contributed to their



invisibility in public life. Through their shared activities, the participants have been enabled to create ways for asserting their presence and reimagining their identity. In this regard, this organisation has provided the participants with opportunities to replace the pejorative characterisations imposed upon them with a more empowering identity that is the identification of PWD as competent individuals. By representing themselves as competent individuals, the participants have been enabled to set themselves as role models for other PWD in their community.

The participants' collective spirit to develop themselves as role models for other PWD in the area is clearly reflected in a mural painted on a wall inside FPDB office. The photo of this mural is presented in the following figure:



Figure 5. A mural in FPDB Office

Figure 5 depicts a picture of two PWD in a street intersection. One is on a modified motorcycle and the other one is sitting on the street and appears to be a beggar. The man who is on a modified motorcycle is saying to the beggar “*Ayo makaryo!!!*” (Local Javanese language for “Let’s work!!!”). When I asked the participants about the meaning of the mural,

they consistently explained that the mural represents their aspiration to be able to encourage other PWD in the area to free themselves from their subordination (symbolised by the beggar) by doing dignified jobs (symbolised by the man on the modified motorcycle).

This mural, along with the participants' social interactions and shared activity, has become the medium through which the participants express their aspiration to be a role model by asserting their identity as competent individuals. In this sense, FPDB has functioned as a transformative site by creating symbolic tools for the participants to contest and alter the subjugating narratives of disability. Consistent with Rappaport's (1995, 2000, 2011) analysis, through symbolic mediums, such as mural and art performance, marginalised groups can create stories and images that function as a powerful resource to envisage empowering shared narratives. Similarly, Harter et al. (2006) argue that developing alternative shared narratives are instrumental in enabling PWD, "to break free from dominant societal scripts that often reduce them to their disability and exclude them from the public sphere" (p. 12).

### **8.3.3. Let our work do the talking.**

The concept of *let our works do the talking* represents a strategy used by the participants to replace the deficit-oriented labelling commonly imposed upon them with empowering identities that are centred on the participants' works and achievements. This strategy indicates that having a job for the participants is not simply a matter of being able to make a living. Rather, the participants' reflections suggest that having a job is symbolically meaningful as such an achievement may allow them to challenge the deficit-oriented narratives of disability. Ilham's reflection provided a detailed account on this strategy:

We should not focus on our disability, but on our works ... when we can create good products, people will look at our ability, not our disability. When we market our products by selling our disability, then only those who have concern on disability will

buy our products. We won't be able to compete fairly in the market by selling our disability. What we should do is to let our works do the talking (Ilham, male, FPDB coordinator).

Ilham's reflection suggests the empowering meanings of being able to place works and abilities as the cornerstone of his identity. His comments indicate that by positioning his work and abilities as the focus of his identity, he can challenge the common demeaning practices of making disability as a 'commodity' that is often marketed to evoke others' pity. In this sense, Ilham's reflection enacts the message visualised in the mural that is presented in Figure 5. By emphasising works and abilities as the central features of his identity, Ilham has been able to resist the demeaning stereotype of PWD as self-pitying individuals, which is symbolised by the picture of a beggar in the mural. Such a resistance is further illustrated by Ilham's reflection:

We should get money because people are appreciating our works, not because they pity us. I learnt that myself after the earthquake. With one of my hand was on sling, I had started working by selling nursery plants. I met friends who had been living with disability since before the earthquake and that motivated me. They didn't say much and just kept working. Without saying much, they kept working, doing whatever they can do. That was when I started to think about doing whatever I can do to have income. I realised that it is much more satisfying to get income because we work for it, not because people give us (Ilham, male, FPDB coordinator).

In addition, Ilham argued that PWD's ability to thrive in their profession is a key to change society's view on disability:

When a *difabel* friend is successful with his enterprise and he is even able to employ non-disabled people, I think people will no longer think of his disability. Instead, his society will think of him as an entrepreneur, he can run a business, he is a successful man. Eventually, the way people look at him will change by itself. We don't need to yell, we don't need to demand this and that. When we can show that we have something that we can develop, our society will be able to see that. We may have not made a big success, but if we are persistent in doing our business ... people will not look at us with a pity. Rather they will consider us as a hard worker.

Overall, Ilham's reflections suggest that participating in FPDB is about countering the 'deficit-focused' labelling generally imposed upon PWD, by promoting 'potency-focused' narratives, such as the narratives of being a successful entrepreneur or socially active community member. Furthermore, Ilham's reflection indicates that asserting his identity as a competent individual is crucial for promoting an awareness that the problems with disability have been generally caused by the dominant stigmatising views on PWD, rather than by factors within the PWD themselves. This point is found to be evident in Puan's reflection as she shared how participating in this organisation has changed her views on disability and PWD.

Puan is a non-disabled person. After the earthquake, she was recruited by KARINAKAS based on her expertise as a physiotherapist to provide home-care for those who sustained long-term injury because of the earthquake. It was through this role that she met for the first time with some of the early members of FPDB. Some of the early members of this organisation were her 'clients'.

Back then, honestly, as a physiotherapist, I always had the urge to correct these friends' body postures whenever I thought they were walking or carrying their body in

wrong ways. But then from these friends, especially those who have been living with disability since long before the earthquake, I learn that their standard is not about what is assumed as normal, but what is most comfortable for them. So it is not important whether or not they use their assistive devices in theoretically correct ways, as long as they are comfortable ... it makes me realise that doing the therapy was my will but it might not be what made these friends feel comfortable. It opened up my point of view on what used to be my and my friends' way of thinking at the hospital. They did not think of how the patient feels about it, the only thing they care was meeting their target as a physiotherapist, what are considered as an ideal practice according to the physiotherapist, they did not refer back to the patient (Puan, female, FPDB secretary).

Puan's reflection suggests how her interactions with fellow FPDB members have changed her point of views on disability. Particularly, her reflection indicates that through such interactions she has been enabled to gain critical awareness of her own taken for granted patronising assumptions on PWD and how these assumptions may contribute in sustaining the dominant oppressive narratives on disability. Drawing on such a reflection, it can be concluded that the transformative feature of FPDB as an empowering setting is related to its ability to promote alternative identity narratives through which its members can reject and replace the impairment-focused representations of PWD. As argued by Goodley & Tregaskis (2006), the struggle of PWD for equality and meaningful inclusion often involves rejections toward the prescribed meaning systems that "prioritise pathological certainty over enabling possibilities" (p. 644).

#### **8.4. From an Object of Pity to Contributing Community Member**

This sub-category represents another empowered outcome generated in FPDB. *From object of pity to contributing community member* captures the participants' reflections which

indicate the transformative shift experienced by the participants as a result of engaging in the social interactions and shared activities that have occurred in FPDB. The participants' reflections suggest that through their involvement in this organisation, they have been able to transform the ways they view and experience themselves. From previously, viewing themselves as dependent and useless individuals, the participants are now able to assert themselves as independent and competent community members who can make meaningful contributions to the betterment of other people in their community.

The data analysis led to the identification of three mechanisms through which the participants have been enabled to experience such a transformative process. These three mechanisms include:

- Countering the dependency narratives.
- Countering the 'aid mentality' phenomenon.
- Promoting socially oriented practices.

I discuss each of these mechanisms in the following sections.

#### **8.4.1. Countering the dependency narratives.**

*Countering the dependency narratives* is a concept that represents the participants' proactive attempts to disrupt the dominant portrayals of PWD as dependent individuals. The following quotations illustrate forms of practices that sustain the negative portrayal of PWD as dependent individuals, which were observed and experienced by the participants:

Sometime ago, I attended a socialisation session on accessible general election organised by the KPU [*Komite Pemilihan Umum* or the General Election Committee]. They encouraged us to report to them if we found any election post, which was not accessible for *difabel* people. I shared this information with other villagers in my village, and their response was, "why bothered of installing ramp and make the election

post accessible, let's just carry them to the election post, we help them". But, it would be impossible for me to report my village to the KPU for the election coordinator in my village was my older brother, it would be like I reported my own brother. So yeah, the society still puts a pity on us (Jalu, male, FPDB member).

There are many inappropriate practices conducted by the department of social affair ... for example providing poorly organised training programs, such as organising an electronic course in which the only thing that the participants had to do was to watch a video on how to repair a mobile phone ... the department of social affairs provides training programs without ongoing supports after the trainings, it seems that they make attending training programs as the profession of *difabel* people (Puan, female, FPDB secretary).

We think that we have been treated as an object, being positioned as an object. That makes us start to think, "will we be an object forever?" and that's what develops our critical voices (Amir, male, FPDB member).

The three quotations above illustrate how the demeaning narratives of PWD as dependent individuals have been reproduced in the participants' experiences. Jalu's experience shows how such practices have been manifested in his community life. Puan's observation suggests how similar practices have been institutionalised. Through such practices, the participants' identities as autonomous and determined subjects have been denied. Consequently, as pointed out by Amir, the participants have come to awareness that they have been predominantly treated as an object.

Driven by such negative experiences, the participants' reflections further suggest that the value of FPDB as an enabling social environment is related to its role in fostering the participants' independence:

We are encouraging our friends to work and not being dependent to others. When there is a friend who still merely thinks about looking for aid, then it means that he doesn't have the spirit of FPDB ... In our conversations, we often say this to our members who are still young, "now, it is your parent who is taking care of you, but whether you can do it or not, there will come the time when you should take care of your parent. Whether you are in wheelchair or not, there will come the time for you to take care of your parent. Are you going to be a person who just wants to be looked after forever? So, we talked through this kind of thing, so that they start thinking about their mentality, don't just think about getting help, help and help (Ilham, male, FPDB coordinator).

Ilham's reflection suggests that conversations between FPDB members have become an important medium to promote the participants' resistance against the dominant portrayal of PWD as dependent individuals. Through the conversations that they have with each other, the participants have been encouraged to develop critical attitudes toward patronising practices that have sustained their marginalisation. Such attitudes are reflected in Puan's comment:

I can't say that one hundred percent of FPDB members have had critical views.

Perhaps, only Agus and Ilham who have been able to really live our critical views.

But, at least, some of us have been able to realise that the department of social affairs has not used the right ways to treat us. That is not how an empowerment should look like (Puan, female, FPDB secretaryFPDB Coordinator).



Puan's reflection suggests that this organisation has enabled the participants to gain critical awareness about the socio-political mechanisms that have produced and sustained their subordination. Such a reflection indicates that the transformative value of FPDB is related to its ability to foster the participants' critical understandings of their oppressive experiences as well as the socio-cultural and political context that have produced such experiences. As argued by other scholars (Freire, 1996; Kagan & Burton, 2010; Prilleltensky, 2008), the role of an empowering setting as a catalyst of conscientisation plays a key role in promoting marginalised individuals' personal and collective acts of resistance.

#### **8.4.2. Countering the 'aid mentality' phenomenon.**

In the previous section (8.4.1), I discuss how the perpetuation of dependency narratives has become one of the social mechanisms through which the subordination of PWD are reproduced and sustained. In the participants' local communities, the perpetuation of dependency narratives had been complicated by a particular situation that emerged in Bantul during the post-disaster period. The presence of a large number of charity programs during the emergency and recovery stages had created what was identified by the participants as the 'aid mentality' phenomenon.

Drawing on the participants' reflections, the phrase of 'aid mentality' refers to a set of psychosocial challenges that have emerged in the affected local communities as a result of being accustomed to charity styles aids or donations. One of the psychosocial challenges has been the difficulty to invite people's involvement in a community-based program when the program does not provide direct aid or donation like what was done by some humanitarian agencies during the post-disaster period. The following two quotations from (FPDB coordinator) illustrate his observation of such challenges:

The practices of providing fee for *difabel* people who attend training programs are really, really damaging. Such practices damage the mentality of *difabel* people ... they become exclusive, lazy and dependent.

Often there is no accountability in how people spend the aid they get from the government. They may just send some receipts which people can make themselves, anyway. There is no control from the government of how the money used. This kind of practice can damage the mentality of our friends ... one person can receive aid for several times, while there is other who never receive any.

In addition, my interviews with the staff of KARINAKAS and community activists from the villages that were involved in the CBR program, also confirmed the presence of this 'aid mentality' phenomenon:

Another challenge in organising our *difabel* friends was *difabel* people in Indonesia had been accustomed to the programs from the department of social affairs, in which they always got money whenever they were involved in an activity. So, it was hard for us at the beginning when we wanted to stop this kind of practice. When we tried to invite people for the first time their very first question was always "how much money will we get?" We can understand why they have such an attitude but when this attitude becomes a mindset, it is very difficult for us ... moreover after the earthquake there were many NGOs which provided aid ... so when we first approached the community without offering money, people were like, "over there, there is this organisation which gives us this and that, are you really want to help us, why don't you give us aid?"

(Dino, male, KARINAKAS CBR program manager).

The situation after the earthquake has fostered volunteering spirit in some of us. But, the disaster has also brought the opposite. What I mean is, whenever there is a proposed community activity, the first thing people now ask is “what sort of aid that we will get with this activity”. And that is happening everywhere, because I am involved in a community development program, so I have visited one village after another (Soleh, male, a community activist).

Situated in such a context, the participants’ reflections suggest that the value of FPDB as an enabling social setting is related to its ability to counter this ‘aid mentality’ phenomenon by nurturing social or volunteering spirit. The participants’ experiences suggest the presence of collective practices that have encouraged the participants to maintain their involvements in this organisation, although such involvements may not always bring direct benefits for them. In contrast to the ‘aid mentality’ phenomenon, the participants reported that participating in FPDB have encouraged them to nurture altruistic attitudes and prosocial behaviours:

Based on what I see and experience, the distinctiveness of FPDB is on its togetherness, that feeling of togetherness. Whether we are the have or the have nots, we prioritise our togetherness, for example when we like to have a meeting and we don’t have anything to organise a meeting then we will contribute whatever we have to make that meeting happen (Amir, male, FPDB member).

Friends here are still willing to come and gather although they don’t get anything, they still come (Jatmiko, male, FPDB member).

We have a social spirit. Perhaps if friends here do not have this social spirit they would have left FPDB for PPDI [a government sponsored disability organisation],

because in PPDI people will not go on with an activity unless they get money, while in FPDB we may even need to put some money from our own pocket to help others, ... we don't offer grant, we don't offer money, so if we don't have that social spirit, we will be reluctant to work, we will be asking for transport fee, meal fee ... but because we have the social spirit, because we have been educated, so we keep working although we are not paid in return. But we are happy because we help others who face similar struggle (Astuti, female, FPDB member).

The three excerpts above suggest that FPDB has functioned as an empowering setting by enabling the participants to counter the existing disempowering mentalities through an emphasis on socially oriented practices. Such an emphasis has also allowed the participants to challenge conceptions that they need handouts. In this regard, participating in FPDB has promoted solidarity and generated support to collectively resist the social pressures that demand the participants' conformity to the existing disempowering mentalities. Similar with a study conducted by Harter et al (2006) on a counter-narrative of disability, the participants' experiences with FPDB indicate that this organisation has introduced them to alternative way of being through which they may dismantle the subjugating narratives of disability. In addition, such a finding also underlines the importance of alternative shared narratives as both a resource and target of social changes (Rappaport, 1995; 2000, 2011).

#### **8.4.3. Promoting socially oriented practices.**

When I asked the participants about what they value most on being part of FPDB, one of the points frequently mentioned was its emphasis on socially oriented practices. The participants appeared to highly appreciate the opportunities that they have to be involved in shared activities through which they can help or support others, not only FPDB members but

also those from outside this organisation. The participants reported that they value their involvement in FPDB as it provides them with opportunities to translate their togetherness and social spirit into concrete acts of helping others.

Drawing on such reflections, *promoting socially oriented practices* is a concept that captures the participants' enjoyment of being able to engage in socially oriented activities and the meanings that they ascribe to such activities. The following quotations illustrate the participants' responses when I asked them about what they like most of being involved in this organisation:

I can be a useful person for other people, for my friends (Ranto, male, FPDB member).

I am happy and proud, that through FPDB, I can be a useful person for others, I can help other people, care for others. First, I am happy, second, I am proud (Amir, male, FPDB member).

Simply because it is psychologically fulfilling, I like it, happy to be able to help others (Tulus, female, FPDB member).

The participants viewed that the socially oriented activities nurtured in FPDB have become a defining feature of this organisation:

With the wheelchair service centre, the social service comes first, and the business comes second ... because our principle is to provide social service, we will think about the business side of it later on, because there are many friends who need it, not only among us but other people as well ... so we keep trying to do the best for our friends who are in need ... and that is the spirit of FPDB. From Monday to Saturday

there are always a couple of us who are on duty of staying at the office as a contact person and we are not getting paid for doing that. If we don't have that social spirit, we won't be willing to do that. It is a rarity nowadays to meet people who are willing to do such a thing (Cahyo, male, FPDB member).

We can help our friends who use wheelchair or crutches when they are having a problem with their assistive devices, when their devices cannot function properly, while other organisations may just organise seminars without actual implementation. But in FPDB we have the wheelchair service centre ... that the realisation, that's the difference (Luna, female, FPDB member).

The reflection of Cahyo and Luna above suggest that the socially oriented practices nurtured in FPDB appears to be a rare opportunity as not many organisations in their community have been developed with a similar orientation. Such a reflection implies that the value of FPDB as an empowering setting is related to its ability to nurture alternative collective practices, which has enabled the participants to provide meaningful support for others. The participants seem to believe that their involvement in such practices may bring changes in the way society views PWD, that is from a 'passive help receiver' to a 'capable helper'. The following quotations illustrate such a belief:

In a way we show to others, we develop strategies so that people can see us ... we do not do a mass demonstration here and there, but with no realisation just an empty talk ... we try to show people first so that people are interested to know about us, "what sort of group is that? Why there are always people who gather in that place and they use wheelchair?" and then gradually they will learn that "Oh, ... I see it is a wheelchair service centre" and they will learn that the mechanics are *difabel* persons

and they may say, “Oh, so they are capable” and that will make people recognise us as *difabel* persons who are capable to run a wheelchair service centre, so when they meet a *difabel* person who become a beggar, they will be able to think that not all of *difabel* persons are like that. I think that is where our action is (Luna, female, FPDB member).

With the grant we got from the presidential office ... I hope FPDB can bring benefits not only for *difabel* people. I hope the benefits can also be enjoyed by non *difabel* people. I mean FPDB can also make contributions to non-difabel people, let's not just receiving help from non-difabel people (Harto, male, FPDB member).

Luna's and Harto's reflections suggest the symbolic meanings that the participants ascribed to the opportunities for engaging in socially oriented practices. Their reflections indicate the value of FPDB as a transformative space that has provided them with opportunities to defy the dominant oppressive portrayal of PWD as objects of pity. Participating in this organisation has enabled them to present and assert themselves as competent and contributing community members. Through their social praxis in FPDB, the participants have been enabled to envisage an alternative shared narrative that supports their liberation. Such a finding is consistent with previous research on narrative approaches to empowerment (e.g., Case & Hunter, 2012; Nelson, et al., 2001; Rappaport, 1995; 2000, 2011; Salem, 2011). Similar to these research, the findings of this current study suggest that FPDB has functioned as a supportive context for the participants by enabling them to reconstruct the way they give meaning to themselves and their relationships with others.

In addition, the participants' reflections suggest that having the opportunities to do socially oriented practices are not only politically important but also culturally meaningful, particularly in regard to the participants' spiritual life. Agus, for example, he explained that

his personal motivation to develop himself as a disability activist is rooted in his religious belief, which encourages him to be a useful person for other people:

Back then, I already had my own home-based business, I never had interactions with all of these friends because I already felt comfortable in my own little world.

Financially speaking, I had had good income. But then, there is this teaching that says, “you are at your best when you can be a useful person for other people” (Agus, male, FPDB coordinator).

Similarly, Ilham also made a reference to a particular teaching in the Javanese belief system and philosophy (i.e., *Kejawen*) when he shared what have motivated him to be actively involved in this organisation:

When I am willing to share my life with others, I am living my *dharma* [the spiritual duty of life]. I am not a human being unless I do so ... when I am sharing my life with others, in a way I am fulfilling my *dharma*. As a human being I will always be connected to other people ... when we are willing to practice *pangolahing roso* [contemplating one’s inner self], it means that we are willing to live our *dharma*, the *dharma* of being a human being (Ilham, male FPDB coordinator).

In his reflection, Ilham made a particular reference to the notion of *pangolahing roso*. The term *pangolahing* in Javanese language has a relatively similar meaning with the term contemplating in English, and the term *roso* has a close meaning to the concept of inner life in modern psychology. In the *Kejawen* philosophy, the concept of *roso* is central in explaining the Javanese way of being (Beatty, 1999; Indrajaja & Zaumseil, 2014). This concept suggests that one’s humanity is partly defined by the person’s ability to exercise his or her *roso* as an inner compass to relate with others, with his or her ecological environment and with the



transcendental realm. The concept of *roso* encompasses various elements of one's inner life including sense, feeling, meanings and reason, as the Javanese culture does not view people's cognitive and emotional dimensions as separate entities (Beatty, 1999; Indrajaja & Zaumeseil, 2014).

Drawing on Agus's and Ilham's reflections, it becomes apparent that the significance of FPDB as an empowering setting is related to its ability to function as a social medium through which the participants have been enabled to live their spiritual and cultural existence. In this sense, participating in this organisation has been meaningful not only because it enables the participants to assert their identity as rightful citizens, but also to articulate their wholeness as spiritual and cultural being which have often been disregarded by the dominant oppressive narratives of disability. Such a finding is consistent with the argument that views empowerment as a contextual notion, and therefore, studies on empowering settings need to be sensitive with characteristics which are specific to the socio-historical and cultural context in which the settings are situated (Aber et al., 2011; Maton & Salem, 1995; Riger, 1993)

## **8.5. Chapter Summary**

Key findings presented in this chapter suggest that 'mindset changes' is the general feature that represents the empowering outcomes experienced by the participants as a result of being actively involved in FPDB. The participants' reflections indicate that this organisation has introduced them to alternative narratives of disability. Through these narratives they are able to gain critical understandings of their personal and collective struggle, particularly in regard to the socio-cultural and political mechanisms that have sustained their oppression.

Overall, the participants' reflections suggest that their 'mindset changes' have been facilitated by two enabling mechanisms. These include: (a) having critical awareness of and determination to reject the internalisation of the dominant oppressive narratives on disability,

and (b) proactively replacing the deficit-oriented representations of PWD (i.e., PWD as helpless, dependent and inferior individuals) with potency and achievement focused identifications (i.e., PWD as capable and contributing community members). These two enabling mechanisms suggest that FPDB has not only been pragmatically useful but also symbolically meaningful, as it enables the participants to re-envision their personal and collective identities in ways that promote determination and sense of agency.

Furthermore, the overall findings presented in this chapter suggest that this organisation has enabled the participants to create empowering shared narratives, which convey stories of solidarity and resistance. The participants' reflections further indicate that the opportunities to engage in socially oriented practices have played a key role in promoting their stories of solidarity and resistance.

## Chapter 9

### Discussion

The aim of this study was to investigate the nature and dynamics of FPDB as an empowering setting. I specifically examined the socio-psychological processes and mechanisms that have enabled this organisation to function as a transformative site for the participants to challenge the ongoing discrimination and marginalisation imposed upon them. In this chapter, I present an overall discussion that provides theoretical responses to the research question explored in the current study. The aim of this chapter is to outline grounded theoretical interpretations, which are contextual to the particular locality in which this study is situated. Furthermore, I also discuss the extent to which the theoretical interpretations are consistent with or extend existing theories in the related fields.

I draw and expand on the two conceptual categories presented in the findings chapters (i.e., *FPDB as a transformative incubator* and *FPDB as a mindset changer*) to develop the theoretical interpretations of the current study. I analyse the interconnections between these two conceptual categories and use the analysis to explain the overall processes and mechanisms, which have characterised FPDB as an empowering setting.

#### **9.1. FPDB as an Empowering Setting: The Enabling Processes and Mechanisms**

Figure 6 represents the overall theorisation that explains the mechanisms and processes of FPDB as an empowering setting.

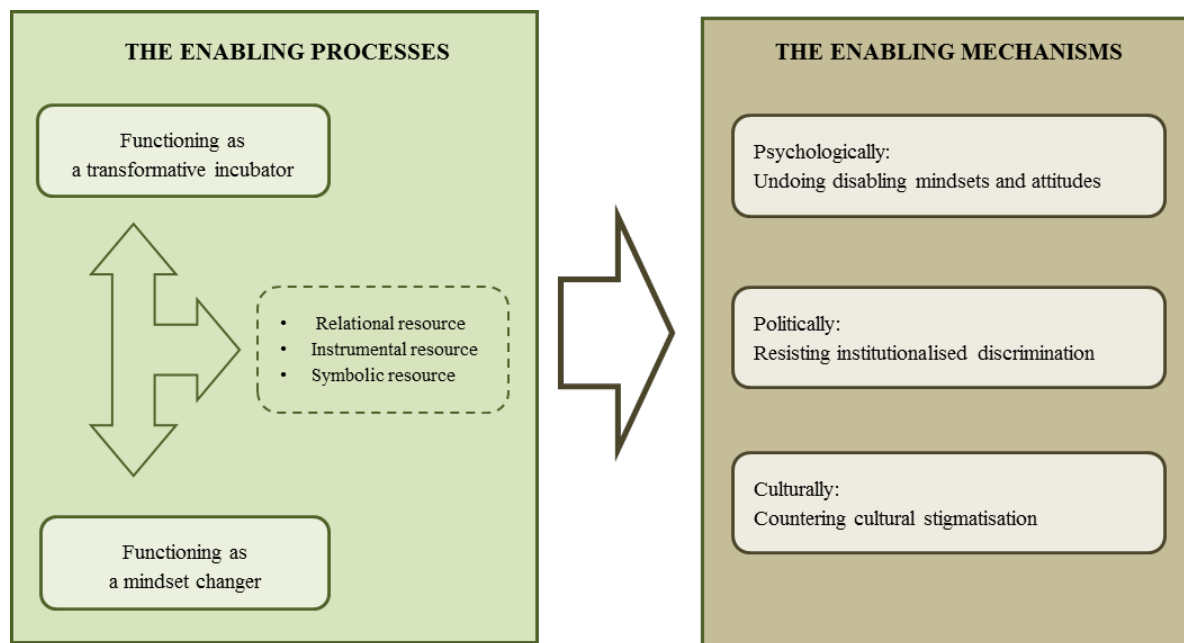


Figure 6. FPDB as an Empowering Setting: The Enabling Processes and Mechanisms

Drawing on the data analysis, I identified two enabling processes, which have contributed to develop this locally initiated disability organisation as an empowering setting. The first process represents social practices in FPDB, which have enabled this organisation to function as a transformative incubator by developing the participants' capacity to collectively tackle their social and economic marginalisation. The second process explains the role of this organisation as a mindset changer that enables the participants to transform their understandings of and responses to disability.

The data analysis further suggests that through these two processes FPDB has generated three types of enabling resources, including relational, instrumental and symbolic resources. By providing the participants with these resources, this organisation has been able to cultivate the participants' resistance against the psychological, political and cultural dimensions of their discrimination and marginalisation.

I use Figure 6 as a conceptual map to detail the theoretical interpretations of the current study as presented in the following sections.

## **9.2. The Enabling Processes**

The term ‘enabling processes’ refers to a range of collective practices that have over time developed FPDB as an empowering setting by functioning as both a transformative incubator and mindset changer. As a transformative incubator, this organisation has provided the participants with opportunities to develop meaningful social connections and alliances, as well as possibilities to accumulate knowledge and practical skills. By creating such opportunities, FPDB has assisted the participants to gain relational and instrumental resources. These resources include psychological supports, broader social networks and job opportunities. All of these are crucial for developing their individual and collective capacity to tackle their multi-dimensional disadvantages.

As a mindset changer, this organisation has generated transformative understandings of disability, which enable the participants to refute the dominant representation of disability as a form of personal inferiority. In other words, FPDB has created pathways for the participants to transform their mindsets with regard to how they give meaning and respond to their disabilities. This organisation has acted as a mindset changer by creating social medium (e.g., discussions, informal conversations, group rituals), which enable the participants to gain critical awareness of the social systems and practices that have produced and sustained their marginalisation. As a result, through their involvement in FPDB, the participants have been able to shift their perspectives of disability by adopting the understandings of disability as a form of social injustice.

The mindset changes experienced by the participants have then become a catalyst for them to develop both personal and collective acts of resistance. The participants’ acts of resistance are partly manifested through the enabling practices (e.g., maintaining emancipatory relationships, forging solidarity, and promoting economic independence), which have characterised FPDB as a transformative incubator. Such practices demonstrate the

interconnections between the two enabling processes that have characterised FPDB as an empowering setting.

Furthermore, the overall findings of this study suggest that the meaning and potential of FPDB as a transformative setting are related to its ability to generate three types of enabling resources: (a) relational, (b) instrumental, and (c) symbolic. Each is detailed in the following sections.

### **9.2.1. Relational resources.**

Social exclusion has been a common form of social disadvantage experienced by many PWD in Indonesia, including FPDB members (Adioetomo et al., 2014; Miranda-Galarza et al., 2013; Yulianto, 2015). The participants' experiences suggest the existence of pervasive physical and socio-cultural barriers that have impeded their opportunity to develop meaningful social participation in their community. As a result, like many PWD in Indonesia, the participants have been at risk for experiencing social isolation and disconnection along with the detrimental effects of these negative social circumstances, such as loneliness and hopelessness (Miranda-Galarza et al., 2013; Yulianto, 2015).

For the participants, social exclusion has not only caused negative psychological consequences, but has also brought a range of material disadvantages. Their experiences suggest that having limited social connections has also resulted in restricted access and opportunities to obtain sustainable livelihoods. The participants' disconnection from the social networks in their community have narrowed their opportunities to access relevant information, capacity building programs and a chance for employment, which are all essential for obtaining sustainable livelihoods. The participants' experiences are in line with extensive research that has underlined the direct link between the social marginalisation of PWD and

their economic disadvantages (e.g., Adioetomo et al., 2014; Barnes & Mercer, 2003; Schriner, 2001; Yulianto, 2015).

In the Javanese cultural context, the participants' social and economic marginalisation may have been intensified by the nature of Javanese social life, which demands one's active involvement in the community's collective activities and rituals (Guinness, 1986; Koentjaraningrat, 1989; Mulder, 1996; Newberry, 2007). Through such involvement individuals validate their sense of belonging to the community, and thereby secure their access to community resources and support (Guinness, 1986; Koentjaraningrat, 1989; Mulder, 1996; Newberry, 2007). For those who live in Javanese rural areas, maintaining good connections with their fellow villagers is not purely to meet cultural expectations. It is more than that, such connections play a crucial role in securing people's social and economic survival (Guinness, 1986; Newberry, 2007). As the Indonesian Government has not been able to provide reliable and adequate public services, individuals often have to rely on their immediate social networks in order to meet their basic needs (Guinness 1986; 2009). In such a context, people need to maintain their social connections, so that they can take part in the mutual exchange of information, goods and services, which are shared between households (Guinness, 1986; Newberry, 2007).

Situated in such cultural and political contexts, the participants' social and economic marginalisation reflects their limited opportunities to be part of the mutual exchange networks, which have shaped the nature of community life in their village. Consequently, the participants also have fewer opportunities to access community resources, which are available through the social networks existing in their village. Against such a backdrop, the overall findings of this current study suggest that the significance of FPDB as a transformative social setting is related to its ability to generate relational resources that enable the participants to circumvent their social and economic marginalisation.

In the case of FPDB, relational resources refer to social relationships that are proactively developed and maintained to promote emancipation as well as to generate a range of psychological and material benefits for the participants. The participants' experiences indicate that through their involvement in this setting, they have obtained opportunities to develop empathic, caring, supportive and family-like relationships based on egalitarian, genuine and trustworthy interactions. These relationships have then enabled the participants to experience a range of psychological and material benefits that are crucial for supporting their daily struggle against various forms and consequences of social marginalisation. These psychological and material benefits include overcoming social isolation, reducing psychological distress, feeling supported as well as having helpful networks that provide them with necessary material assistance in times of need.

The role of interpersonal factors in shaping the nature of empowering settings has been explored in a number of studies (e.g., Aber et al., 2011; Kirk et al., 2015; Maton & Salem, 1995; Odahl-Ruan, McConnell, Shattell & Kozlowski, 2015; Peterson & Speer, 2000). Some scholars have suggested that opportunities to experience emancipatory relationships are central in the development of empowering settings because such relationships nurture a sense of belonging and cohesiveness, which may then generate group solidarity and collective agency (e.g., Balcazar et al., 2012; Maton, 2008; Maton & Brodsky, 2011; Mejias, Gill & Shpigelman, 2014). Consistent with these studies, the participants' experiences suggest that togetherness is a key feature that defines their involvement in FPDB as an enabling experience.

In FPDB, this sense of togetherness has been partly developed and maintained through what I identified as rituals of compassion and friendliness (e.g., visiting a friend who is sick or grieving, inviting friends over to have a meal together). It is through such practices that a sense of belonging is nurtured in this organisation. As the literature suggests, a sense of



belonging in FPDB seems to generate “a feeling that members matter to one another, the sense that they matter to the group in general” (Cronick, 2002, p. 536). Such a finding is consistent with Maton’s (2008) analysis, which notes a sense of community as one of the features that characterise empowering settings. A sense of community that entails a feeling of belonging may generate shared emotional connections among a setting’s members. This kind of connection plays a key role in enabling a setting to function as a supportive network (McMillan & Chavis, 1986). In this regard, FPDB has provided the participants with relational resources that enable them to experience a sense of community within and beyond the setting through ongoing supportive, family-like relationships (Maton, 2008).

Bagas, one of the participants reflected that the spirit of togetherness in this organisation has been manifested through what he identified as the attitude of “*ayo dihadapin bareng*” (Let’s deal with it together). With this expression, Bagas described how in FPDB people are motivated to become a source of encouragement for each other and to not allow members to face their ordeals alone. Instead, this participant recalled that in the organisation people were encouraged to transform their personal ordeal into a collective struggle. Such a finding reflects the understanding of empowering settings as a space where individuals can experience enabling social relationships that may then promote their sense of community (Keys et al., 2017; Maton, 2008; Neal, 2014; O’Donnell & Tharp, 2012; Sonn & Fisher, 1998).

As a relational community, FPDB has created opportunities for participants to gradually build a shared history, worldview, values and emotions. In this regard, the participants’ experiences seem to reflect the argument of O’Donnell and Tharp (2012) which suggest that individuals may develop intersubjectivity as they engage in shared activities that generate psychological commonalities. Cronick (2002), in particular argues that intersubjectivity may foster a cohesive feeling of “we-ness” (p. 538). Consistent with these

arguments, the findings of this present study suggest that FPDB has enabled the participants to develop intersubjectivity as they engage in collaborative actions to tackle their shared struggle. The participants' reflections further indicate that intersubjectivity has played a key role in promoting a shared understanding of 'we-ness', which then function as a springboard for developing their solidarity and collective agency.

### **9.2.2. Instrumental resources.**

Instrumental resources refer to tangible opportunities and supports, which are proactively created and shared among FPDB members, through which the participants can acquire a range of material benefits. These resources include opportunities for developing knowledge and practical skills as well as possibilities for expanding the participants' social network and obtaining employment. Through such opportunities, the participants have been able to develop their personal and collective capacity such as gaining organisational skills, being connected to broader networks of disability movement in the area, as well as having access to relevant information on disability issues.

These resources have been generated through both formal and informal collective activities, such as via the regular monthly meetings and discussion forum, the wheelchair service centre and the casual daily gathering in the FPDB office. These activities have enabled the participants to share and exchange relevant information, practical skills, as well as technical support. For instance, through their involvement in FPDB, the participants can help each other in dealing with the complex procedures and bureaucratisation for accessing health insurance provided by the national government for low-income families. For participants who have been employed as mechanics and administration staff at the wheelchair service centre, this organisation has provided them with direct material supports in the form of ongoing employment and income.

In Indonesia, where poverty has often become the material context of oppression for many PWD, economic empowerment is considered a key determinant of promoting equitable opportunities and living conditions (Suharto, 2011; Yulianto, 2011). Such a context explains why the participants highly valued the ability of FPDB to provide them with a range of instrumental supports, which may enable them to achieve economic independence. Making efforts to obtain a sustainable livelihood is of the utmost importance for the participants, as they believe that economic independence is a key to equality. As suggested in the literature, some of the participants' experiences suggest the intersection of disability and poverty in producing and sustaining the marginalisation of PWD (Barnes & Mercer, 2003; Schriner, 2001; Thomas, 2002). In this regard, FPDB appears to function as an enabling setting by providing the participants with a space where they can make a collective effort to obtain a sustainable livelihood.

There has been a great deal of research suggesting that instrumental resources, such as opportunities for skill development and meaningful roles, are key mediators in the development of empowering settings (e.g., Balcazar et al., 2012; Maton & Brodsky, 2011; Maton, 2008; Maton & Salem, 1995; Seidman & Tseng, 2011; Silva & Langhout, 2015). Such opportunities often provide the setting members with direct empowering effects at the individual level by fostering a sense of mastery and efficacy, as a result of gaining competence, knowledge or practical skills (Maton & Brodsky, 2011; Maton, 2008). In line with these scholars, the findings suggest that FPDB has been able to act as an empowering setting by creating an alternative site for the participants to accumulate knowledge and practical skills. It is highly unlikely that the participants would be able to access similar capacity building opportunities from existing mainstream institutions or public service providers, due to the pervasive discriminatory systems and practices (Adioetomo et al., 2014).

### **9.2.3. Symbolic resources.**

The overall findings of this current study indicate that the ongoing discrimination and marginalisation experienced by the participants have partly arisen and been sustained through the dominant representation of disability as a form of personal inferiority. The participants' experiences indicate how such a representation has been pervasively manifested and circulated through the ways individuals talk about and respond to disability. As generally found in Indonesia, disability in the participants' community is still associated with a range of subjugating personal labels and negative reactions, such as notions of imperfection, karma, abnormality and feelings of pity, shame, embarrassment, disgust and fear (Adioetomo et al., 2014; Suharto, 2016; Thohari, 2007; Yulianto, 2015). Such a context has created social pressure for both PWD and non-disabled people to view and respond to disability as a form of personal inferiority rather than as social injustice (Suharto, 2016; Thohari, 2007; Yulianto, 2015).

Against such a backdrop, the significance of FPDB as a transformative setting centres on its ability to provide the participants with symbolic tools for resisting the dominant, deficit-oriented representation of disability. As suggested in the literature, symbolic resources in this organisation refer to alternative ways of thinking, different perspectives, ideas and insights that are developed and circulated through conversations, personal stories and artworks, through which the participants can draw transformative meanings and understanding of disability (Zittoun, Duveen, Gillespie, Ivinson & Psaltis, 2003). The participants' experiences suggest that through their involvement in this organisation, they have become familiar with what they identified as 'critical views' of disability.

Drawing on the participants' reflections, critical views of disability refer to frameworks of understanding that have enabled the participants to promote new ways of thinking about disability in ways that are consistent with their struggle for dignity and

equality. By acquiring these new ways of thinking, the participants are then able to refute the dominant, deficit-oriented representations of disability. For instance, a mural painted on the wall of FPDB office has been used as a symbolic tool to visualise and disseminate resistance against the patronising portrayal of PWD as objects of pity. In addition, this mural also represents a shared assertion of self-determination and empowered identity. In this sense, the symbolic resources generated in this organisation have facilitated the process of consciousness raising. As conceptualised by Freire (1996), consciousness raising is a process through which marginalised individuals gain critical awareness of the social forces that shape their oppressive realities. Previous studies on empowering settings suggest that this process is crucial for promoting both personal and collective liberation (Balcazar & Suarez-Balcazar, 2017; Keys et al., 2017; Seidman & Tseng, 2011; Zimmerman, 2000)

Similar to the previous two types of resources, symbolic resources generated in this setting have also functioned as a crucial means for developing the participants' personal and collective capacity to circumvent their ongoing discrimination and marginalisation. By developing and circulating transformative meanings of and responses to disability, this organisation has enabled the participants to change the language and manner in which they approach the issues of disability (Steffensmeier, 2010). Consistent with previous research on the role of symbolic resources, FPDB has demonstrated its empowering function by providing the participants with reflective tools to make sense of their life experiences in ways that augment their personal and collective agency (Balcazar et al., 2012; Case & Hunter, 2012; Zittoun, et al., 2003). As a result, the participants have been able to utilise such resources to invalidate and contest the hegemonic views on disability, which have perpetuated their subordination.

The notion of empowerment has often been understood as intentional and ongoing processes through which marginalised individuals can make a collective effort to gain greater

access to and control over valued resources (e.g., Oliver, 2009; Perkins & Zimmerman, 1995; Rappaport, 1987; Riger, 1993; Zimmerman, 2000). Consistent with this understanding, the findings of the current study suggest that the nature of FPDB as a transformative setting has been materialised through its ability to generate access to relational, instrumental and symbolic resources.

FPDB as a resource centre is primarily a product of a deliberately developed social network with particular values and purposes. As reflected in the participants' accounts, it is through this social network that FPDB has been able to generate a range of both tangible and intangible valued resources for its members. Such an understanding is in line with the concept of social capital (Saegert & Carpiano, 2017).

Anchored in the work of sociologist, Pierre Bourdieu, the concept of social capital assumes that the extent and quality of individuals' social networks is positively associated with their ability to access other types of essential resources, such as economic and political resources. In this sense, the amount of social capital that individuals have generally reflects their position in, and how they negotiate, the broader structure that defines their social world (Saegert & Carpiano, 2017). In line with this notion, I found that the significance of FPDB as an empowering setting centres on its ability to generate a constructive social network that can expand the participants' access to valued resources, therefore, enabling them to negotiate with the broader social structure that has maintained their subordination. Such findings suggest the importance of this organisation as a setting that has enabled the participants to make sense of their experiences as well as to consolidate struggle over material conditions and meaning (Barnes & Mercer, 2003).

In the following sections, I outline how the enabling resources generated in FPDB have contributed to fostering the socio-psychological mechanisms through which the participants advance their struggle for equal opportunities and a better quality of life.

### 9.3. The Enabling Mechanisms

The enabling mechanisms refer to socio-psychological pathways through which the participants exercise their agency, as well as enact their resistance against the psychological, political and cultural dimensions of their marginalisation. As suggested in the literature, the term agency refers to the participants' capacity to proactively generate resources and create strategies for improving their status and promoting their liberation (Cleaver, 2007).

By exploring the enabling mechanisms that have been developed in this organisation, I aimed to explicate the social creation of disablement experienced by the participants as well as to highlight how FPDB as a transformative setting has enabled the participants to defy the disabling practices imposed upon them (Goodley & Lawthom, 2006; Goodley & Tregaskis, 2006). In the following sections, I discuss how this locally initiated disability organisation has enabled the participants to recognise and resist the disabling practices that have commonly occurred at multiple levels, from within the intimacy of their immediate social circles (e.g., family, neighbourhood) to the broader context of public policies on disability in Indonesia. Such a discussion may generate a deeper understanding of a topic that has become a central theme in community psychology; that is the role of settings in promoting individual as well as community development, especially for individuals who experience oppression (Case & Hunter, 2012; Rappaport, 1995, 2011; Sarason, 1972; Seidman & Cappella, 2017).

The notion of empowering settings has been discussed as a contextual concept. Discussions about the nature of empowering settings, and how these may promote an individual's agency, are generally placed within specific socio-historical and cultural contexts in which the setting is located (Aber et al., 2011; Maton, 2008; Maton & Salem, 1995). Agency itself is also conceptualised as a relational notion (Cleaver, 2007). As argued by Cleaver (2007), agency "is exercised in a social world in which structure shapes the

opportunities and resources available to individuals, in which appropriate ways of being and behaving are not simply a matter of individual choice” (p. 226).

In line with such arguments, the findings of this present study indicate that FPDB has functioned as a mediating structure between the larger socio-historical and cultural context in which the participants are members and their everyday life experiences (Aber et al., 2011; Rappaport & Simkins, 1991; Seidman & Cappella, 2017). Therefore, it is necessary to develop a theoretical discussion, which reflects the particularity and complexity of the broader context in which this organisation is situated. As suggested in the literature, such a discussion may generate a more detailed understanding of how the participants have experienced their discrimination and marginalisation, as well as how they have developed FPDB as a social space for accessing valued resources and consolidating their resistance (Bond, 2016).

The overall findings of the current study suggest that this organisation has been experienced as an empowering setting by creating three enabling pathways through which the participants can tackle the psychological, political and cultural dimensions of their marginalisation. Each pathway is detailed in the following sections.

### **9.3.1. “The most important thing is our mentality”: Undoing the disabling mindsets and attitudes.**

Ilham, one of the participants used the quotation above to explain his belief that addressing the internalised disempowering mentality among FPDB members is the starting point to their liberation. Ilham’s reflection (which was shared by other participants) represents the gist of the first enabling pathway through which this organisation has promoted the participants’ personal and collective transformation. Informed by such findings, I concluded that FPDB has functioned as an empowering setting by creating a pathway through which the



participants can undo the internalisation of disabling mindsets and attitudes, which have contributed to perpetuating their discrimination and marginalisation.

For many PWD, research has shown that psycho-emotional disablement has become a significant part of their marginalisation (Goodley 2011; Goodley & Lawthom, 2006). Psycho-emotional disablement refers to negative emotions or attributes targeted to PWD as a result of framing disability as a form of personal inferiority (Reeve, 2006). Rooted in the medical model of disability, psycho-emotional disablement generally reflects a view that portrays PWD as abnormal or deviant others. As a result, disability tends to be associated with condescending descriptions including shame, fear, disgust or pity (Hughes, 2012; Mackelprang & Salsgiver, 2015; Reeve, 2006). Psycho-emotional disablement can be manifested in many ways, from subtle gestures in interpersonal interactions to more direct acts of discrimination (Reeve, 2006).

As a result of experiencing pervasive psycho-emotional disablement, PWD may internalise such negative attributes, which may then lead to a range of psychological sequelae such as the loss of confidence, worthlessness and helplessness (Mackelprang & Salsgiver, 2015; Reeve, 2006). The internalisation of such negative attributes may discourage PWD from participating in society as well as undermine their attempts at challenging their subordination (Campbell & Deacon, 2006; Case & Hunter, 2012; Reeve, 2006). Instead, such internalisation may, over time, contribute to normalising the discrimination and marginalisation commonly experienced by PWD (Mackelprang & Salsgiver, 2015; Reeve, 2006).

Psycho-emotional disablement was reflected in some of the participants' accounts when they recalled how they used to view themselves in negative ways, before they joined FPDB. For example, one participant shared how she used to view herself as a burden to

others. Another participant explained how he used to have low self-esteem and socially withdrawn.

The participants' experiences further suggest that their psycho-emotional disablement may have been partly perpetuated through the negative treatment of PWD in everyday interactions in their community. Both the participants' experiences and my observations indicate that it is still common for PWD in Indonesia to encounter demeaning labelling in their everyday interactions. For instance, one participant recalled how his neighbour, who has a disability, was often mocked by his fellow villagers, making a meaningful social life more difficult for the neighbour.

As argued by Thohari (2007), in the Javanese cultural context, psycho-emotional disablement may be intensified by the presence of fatalistic approaches to life, which are related to some aspects of the Javanese worldview. For instance, viewing disability as a form of *nasib* (Javanese notion for personal fate) or associating it with the notion of bad karma (disability as a form of moral punishment for a past wrongdoing) is still common (Suharto, 2016). Such views may propagate a belief that disability and the multitude of disadvantages, which come with it are inevitable personal realities, rather than socially constructed adversities (Makcleprang & Salsgiver, 2015).

Situated in such a socio-cultural context, I concluded that this organisation has functioned as a transformative setting by enabling the participants to recognise the disabling mentality and attitudes that they have internalised and sustained. In other words, FPDB as an empowering setting has created a socio-psychological pathway through which the participants are able to recognise "the micro practices by which privilege and disadvantage come to be produced, sustained, reproduced, embodied and contested" (Weis & Fine, 2012, p. 175). In this regard, their involvement in this organisation has assisted the participants to develop a critical awareness of the social embeddedness of their psychological challenges.

Such a critical awareness has been promoted in FPDB through collective practices, such as reflective conversations and critical discussions, which encourage the participants to question their existing beliefs and views on disability. As suggested by Campbell (2014), such a questioning process may have led marginalised individuals to develop an alternative lens through which they can view their subordination differently. For instance, one participant shared how he used an informal conversation in FPDB to challenge another participant's way of thinking that reflected the internalisation of the dominant, deficit-oriented representations of disability. The conversation was intended to instil a critical understanding that PWD may unintentionally contribute to sustaining their own marginalisation by viewing the dominant, deficit-oriented representations of disability as unchangeable personal attributes.

The role of critical awareness as a catalyst for fostering both personal and collective empowerment has been well established in the empowerment literature (Balcazar & Suarez-Balcazar, 2017; Keys et al., 2017; Seidman & Tseng, 2011; Zimmerman, 2000). Particularly in disability studies, scholars have discussed the liberating effects of having critical awareness about the construction of disability as a form of social oppression (Goodley, 2011; Oliver, 2009; Shakespeare & Watson, 2002). The works of Paulo Freire on critical pedagogy have provided robust arguments on the role of critical awareness as a springboard for concrete acts of resistance by enabling the marginalised to see themselves and their experiences differently (e.g., Freire, 1996; Freire, Freire & de Oliveira, 2014; Freire & Macedo, 1998)

For the participants of this study, critical awareness of the social embeddedness of their psychological challenges has enabled them to enact two forms of resistance. Firstly, such critical awareness has encouraged them to reject the dominant view of disability as a form of personal inferiority. For instance, their rejection has been manifested in collective acts and conversations, which build FPDB members' confidence to participate in social activities in their community. By having the courage to be socially active, the participants aim to

demystify the hegemonic views that have positioned PWD as inferior individuals who do not belong in the community and who deserve to be socially marginalised.

Secondly, the participants' critical awareness has become a catalyst for developing positive self-definition through which they are able to contest the dominant, deficit-oriented views of disability. In this organisation, the development of positive self-definition has been promoted through collective activities that enable the participants to demonstrate their determination and capacity to lead an independent life. Such activities include a collective effort to create sustainable livelihoods and capacity-building opportunities that may promote the participants' economic independence.

In conclusion, the findings from this study suggest that gaining critical awareness of their marginalisation is instrumental in promoting the participants' liberation from the detrimental effects of psycho-emotional disablement. Such a critical awareness has consolidated the participants' agency to invalidate and contest the dominant, deficit-oriented representations of disability. In this sense, the findings of this present study align well with previous research which discuss empowering settings as a space where marginalised individuals can exercise their agency to disrupt the internalisation of oppression and to reconstruct their sense of self in ways that support their liberation (Balcazar et al., 2012; Case & Hunter, 2012; Mejias et al., 2014; Miranda-galarza et al., 2013; Nelson et al., 2001; Salem, 2011). In addition, the participants' experiences are also consistent with the argument which suggests that becoming critically conscious allows people to "identify [themselves] with similar others and feeling a sense of shared responsibility to respond to injustice" (Keys, et al., 2017, p. 222). In line with this argument, the findings of the current study indicate that FPDB has fostered the participants' solidarity and collective resistance by enabling them to gain critical awareness of the social embeddedness of their marginalisation (Balcazar & Suarez-Balcazar, 2017).

Finally, the findings of this study suggest that addressing the psycho-emotional dimensions of the participants' marginalisation is a key part of their journey toward empowerment. In this sense, the significance of FPDB as an empowering setting is related to its ability to create a pathway through which the participants can collectively deal with the socio-psychological manifestations of their marginalisation. Such findings are in line with the ideas of some scholars who suggest that addressing both the larger structures of power as well as the socio-psychological factors that have created and sustained the subordination of PWD are of equal importance (Campbell, 2014; Chaundry, 2011; Reeve, 2006; Weis & Fine, 2012). This argument resonates with the participants' reflection. While they acknowledge the importance of demanding structural changes (which has become the key issue in recently developed disability organisations in Indonesia), the participants believed that such changes may not be meaningful unless there is also a conscientious effort made to promote changes at the individual level.

### **9.3.2. “Let’s not make ourselves an object of ridicule”: Resisting the institutionalised marginalisation.**

Although some disability organisations and activists in Indonesia have started to propagate critical perspectives with regard to disability, the dominance of individual, deficit-oriented models of disability have remained strongly reflected in many aspects of societal thinking and responses to disability (Adioetomo et al., 2014; Suharto, 2016; Yulianto, 2015). In this current study, I found that institutional contexts have become one of the key areas where the prejudicial view of PWD as inferior others are perpetuated. The participants' accounts suggest how some government institutions and officers have played a key role in sustaining institutionalised marginalisation of PWD through social policies and practices, which undermine the rights of PWD to be treated equally, with respect and dignity.

Informed by such findings, I found that FPDB has functioned as an empowering setting by creating a pathway through which the participants were enabled to tackle the institutionalised marginalisation that they experienced. Such marginalisation was manifested in a range of negative experiences when the participants dealt with some government institutions and officers. For instance, they reported that some government institutions still use patronising approaches in the design and delivery of disability intervention programs. They recalled their experiences of participating in such programs, which made them feel objectified for being treated as passive targets of interventions. Such experiences reflect how government institutions might have contributed to sustaining the disempowering representations of PWD as dependent and helpless individuals by undermining their agency and autonomy (Adioetomo et al., 2014; Campbell & Deacon, 2006; Yulianto, 2011)

In the Indonesian context, where independent disability organisations have been recently developed (late 1990s), government departments have for decades been the main public institutions which play a key role in shaping the way disability issues are approached through social welfare policies (Adioetomo et al., 2014; Yulianto, 2011). Through related departments such as the Department of Social Affairs and the Department of Health, the Indonesian government coordinates the delivery of a range of public services and intervention programs, which are specifically targeted for PWD, including the implementation of rehabilitation and social assistance programs (Adioetomo et al., 2014).

Such a context explains why dealing with government officers at various points of their life has become a common experience among PWD in Indonesia. It is generally difficult for PWD in Indonesia to get alternative sources of instrumental supports (e.g., access to rehabilitation and training programs) other than from government institutions due to the limited availability of independent organisations that provide such services (Adioetomo et al., 2014). The situation can be more challenging in rural areas where the presence of independent

disability organisations has been very rare. Such a political context has created a socio-economic pressure for many PWD to be dependent to the social assistance programs provided by the government (Adioetomo et al., 2014; Yulianto, 2011). Puan, one of the participants used ‘the parent and the children’ metaphor to describe what she observed as the dependency model of relation perpetuated by related government institutions.

In the Indonesian political context, the role of government institutions in perpetuating patronising attitudes toward PWD may have been complicated by the legacy of authoritarianism in the Indonesian bureaucratic system (Yulianto, 2011). Theoretically, the authoritarian era in the Indonesian political system was put to an end at the end of 1990s when a major political upheaval brought down the Suharto’s militaristic regime. However, some of the authoritarian practices which characterised the previous militaristic regime, are often still found in the way state bureaucrats and government officers treat commoners. There is still an expectation for people to passively accept any policy implemented by government institutions, even when the policy is violating people’s rights as citizens. In such a context, people in general have been accustomed to feel inferior when they have to deal with state bureaucrats or government officers (Bebbington et al., 2004; Hadiz, 2004).

This following quotation from Tickemayer and Pujiastuti (2012) provides a clear description of how this patronage political system has generally operated in people’s everyday life at the local level. The observation presented in this following quotation was based on the authors’ study that was also conducted in the Bantul district, the same district where the participants of this current study live:

... [L]ayers of village government were constructed to serve as important gatekeepers for Indonesian society. Members of the community were required to obtain a variety of letters and documents from the village head for conducting their lives and livelihoods. Marriages, divorces, and deaths all had to be reported to this office ... However, before coming to this office, they must first obtain signatures from lower level governmental officials, such as the head of the neighbourhood association and the *dukuh*, the head of the sub-villages. These layers of bureaucracy were used to monitor and control members of the community and to create dependency on government agencies, reinforcing government power (p. 80)

Although Indonesia has embarked toward a more democratic political system, the patronising practices as described in the above quotation has not yet completely been left behind (Bebbington et al., 2004; Hadiz, 2004). The participants' experiences suggest the ongoing existence of such patronising practices. For instance, these practices were evident in the difficulties of the participants in accessing government-sponsored health insurance due to the complicated bureaucracy that they had to go through.

Furthermore, in the Bantul District, this narrative of dependency, which has characterised the pattern or relation between commoners and the ruling elites, appears to be exacerbated by a particular socio-political situation that emerged in the post-disaster context. Ilham, one of the participants used the phrase of 'aid mentality' to describe the particular social challenge emerging in their local community as a consequence of how aid had been distributed during the post-disaster period.

The phrase of 'aid mentality' represents the participants' reflections which described how the presence of charity style aids provided by both government and non-government agencies during the post disaster period has complicated the dependency issue among PWD in their community. While acknowledging the significant contribution of such aid for assisting the community's recovery, the participants' experiences and observation suggest that this kind of aid has also created what they described as 'aid mentality'. This phrase refers to the tendency to rely on others' handout to address their challenging situations. A shared concern over such a tendency became one of the factors that encouraged the early members of FPDB to initiate this organisation. Driven by such a concern, they developed this organisation with an aim to promote its members' determination and capacities to lead an independent life.

Situated in such a context, the findings of this present study suggest that the as an empowering setting, FPDB has enabled the participants to resist against the institutionalised marginalisation imposed upon them. Consistent with what has been reported in the literature,



this organisation has provided the participants with collective activities through which they are able to gain valuable resources to challenge the institutionalised practices, which have created and sustained their dependency and inferior status (Balcazar & Suarez-Balcazar, 2017; Maton & Brodksy, 2011; Seidman & Tseng, 2011). By being actively involved in this organisation, the participants have been able to challenge two aspects of their institutionalised marginalisation. Firstly, they have been able to contest the common patronising treatments that have positioned them as dependent individuals. Secondly, participating in this setting has also encouraged the participants to challenge the common political scepticism that has been produced by the long history of authoritarianism in the Indonesian governmental system.

These two enabling aspects are captured succinctly in one of the participants' reflection, Cahyo. "Let's not make ourselves as an object of ridicule" was a quotation from my interview with him that I used to entitle this section. With this quotation, Cahyo described his resistance against the patronising approaches commonly used by government officers in addressing disability issues. For Cahyo, participating in FPDB has been experienced as an opportunity to liberate himself from institutionalised marginalisation that has made him feel ridiculed.

In FPDB, the determination to resist institutionalised marginalisation toward PWD has been manifested in collective practices that can develop the participants' confidence and capacities to lead an independent life. Such practices include promoting egalitarian styles of communication and participative decision-making process in the organisation. This kind of practice is deliberately maintained to contradict what are generally experienced by the participants in their relations with government officers in which they have been usually treated as a passive object of intervention. Through this kind of practice, the participants are enabled to embody and demonstrate their belief that they are equal and competent, and,

therefore, they can invalidate the disempowering representation of PWD as dependent and incapable individuals.

Promoting its members' economic independence has also become an important practice through which FPDB has enabled the participants to challenge their institutionalised marginalisation. Assisting its members to obtain sustainable livelihood has become a central activity in FPDB. The participants' experiences suggest that without having economic independence, there will be more pressure that may lead to them falling into the cycle of dependency that has been reproduced through patronising social welfare policies.

Encouraging critical attitudes toward government policies on disability has become another mechanism through which FPDB members have challenged the institutionalised marginalisation imposed upon them. During the fieldwork I learned how the participants often engaged in lively discussions that critically question the way PWD have been positioned in social welfare policies and programs. Such critical questioning has also been manifested in the participants' involvement in mass demonstrations and public campaigns targeted to criticise patronising disability policies.

In conclusion, the findings of this current study suggest that FPDB has functioned as an empowering setting by enabling the participants to disrupt the existing hierarchical relations of power that have made, sustained and normalised the institutionalised marginalisation experienced by the participants. Such findings underline the importance of unpacking the creation of privilege and subordination, in order to fully understand the nature and consequences of unequal relations (Weis & Fine, 2012).

By enabling the participants to politicise their experiences and situations, FPDB has become a vehicle for the participants to articulate their personal and collective sense of agency. As indicated by other authors, the politicisation of disability issues is crucial to challenge the social hierarchy that has positioned PWD as as passive objects of aid and

intervention (Balcazar & Suarez – Balcazar, 2017; Goodley, 2011). FPDB has enabled the participants to tackle their institutionalised marginalisation (by providing them with both tangible (e.g., capacity development opportunities, employment possibilities) and intangible resources (e.g., courage, solidarity, critical ways of thinking). Past research suggest that such resources are instrumental for developing the personal and collective agency of marginalised individuals (Aber et al., 2011; Maton, 2008).

In addition, the findings of this study also underline the importance of empowering settings as a space where marginalised people can experience self-enhancement mechanisms that help promote their sense of self-worth and humanity (Case & Hunter, 2012). Such a transformation may not directly bring any structural reforms that change the wider power inequalities. Yet, undermining the merit of such a transformation may diminish the possibilities for paving the ways toward gradual broader political changes (Campbell, 2014). In the Indonesian context, where the development of independent disability organisations which are led and run by PWD is still relatively young and rare, the development of FPDB can be seen in itself as a form of political critic and resistance toward the existing conventional welfare system that has systematically depoliticise PWD and disability issues (Yulianto, 2015).

### **9.3.3. “I am living my *Darma*”: Countering the cultural stigmatisation.**

The findings of this study suggest that experiencing some type of stigmatisation has been a part of the multitude of disadvantages commonly experienced by the participants. The stigmatisation experienced by the participants has been reflected in the ongoing reproductions of negative attitudes and behaviours commonly targeted toward PWD in their community. Through such stigmatisation, the participants’ disability has been viewed as a mark of ‘social

disgrace' that disqualify them to have meaningful social participation (Campbell & Deacon, 2006, p. 412).

The participants' experiences further suggest that being seen and treated as an object of pity has become a major form of stigmatisation that they have experienced. Such stigmatisation was strongly reflected in the way the participants' made sense of their involvement in FPDB. For instance, one of the participants, Luna, valued her involvement in this organisation for the opportunity to show to her community that not all of PWD make living by begging for others' pity, as has been generally stereotyped.

The mural painted in the wall of FPDB office also in a way reflects a resistance against the common stigmatisation of PWD as an object of pity. The mural depicts a picture of two PWD in a street intersection. One of them is sitting on the side of the street and appears to be a beggar while the other one is riding a modified motorcycle. The one who is riding a motorcycle is shouting to the beggar in a local Javanese language, asking the beggar to get work. While the mural is intended to propagate the spirit of resistance among FPDB members, this mural also in a way captures what has been perceived and experienced as the most common form of stigmatisation imposed upon the participants, that is, the dominant portrayal of PWD as an object of pity.

In the Indonesian context, the stigmatisation of PWD as an object of pity is generally related to the remaining presence of moral model of disability (Suharto, 2016; Thohari, 2007). Despite the emergence of disability movements, which advocate socially and politically oriented understandings of disability, it is still common for people to link disability with sinful acts or demonic interventions (Suharto, 2016; Thohari, 2007). As a result, disability has often become a source of stigmatisation in which physical impairments are viewed as a marked of spoiled identity or unworthiness that evokes a sense of pity (Lusli et al., 2015; Suharto, 2016).

The ongoing stigmatisation of disability as a mark of unworthiness is reflected in people's tendency to still use the term *cacat* instead of *difabel* to address PWD (Suharto, 2016). The term *cacat* means blemish, flaw or defect, therefore, addressing PWD as '*orang cacat*' (blemished people) entails the stigmatisation of PWD as "have no value, useless and deserved to be discarded" (Suharto, 2016, p. 696). Responding to such a stigmatisation, disability activists and organisation have advocated the use of the term *difabel*. The term *difabel* is the Indonesian version of 'people who are differently able'. As argued by Suharto (2016), a prominent disability scholar and activist in Indonesia, the term *difabel* is "considered more appropriate for respecting differences and recognising abilities of people with impairments" (p. 693). Yet, the use of the term '*cacat*' is still common. For instance, based on his research on three major Indonesian newspapers, Tsaputra (2016) identified that the impairment-focused terms are still frequently used in reports or news about disability.

In the Indonesian context, the stigmatisation of PWD as pitiful individuals has been exacerbated by the systemic economic marginalisation experienced by many PWD (Miranda-Galarza et al., 2013). With pervasive discriminations still prevent many PWD for accessing equal educations and work opportunities, PWD in Indonesia have often been forced to make a living by relying on others' donation or charity. Furthermore, the existing national disability policies have not been able to provide adequate and accessible socio-economic infrastructures that meet the rights and the needs of PWD. As a result, the help from family and friends has often become the only source of socio-economic support for many PWD (Adioetomo et al., 2014; Miranda-Galarza et al., 2013; Yulianto, 2015). These situations have further reinforced the stigmatising views toward PWD. PWD are generally portrayed as dependent, useless, unproductive citizens and a burden to their society, therefore, they are deserved to be pitied (Irwanto et al., 2010; Kamil, Shantini & Sardin, 2015; Kusumastuti et al., 2013).

Such socio-cultural contexts explain why resisting the stigmatisation of PWD as useless, unproductive community members and objects of pity has become a significant part of the participants' struggle against their discrimination and marginalisation. Situated in these broader social-cultural contexts, I found that the significance of FPDB as an empowering setting is related to its ability to create opportunities for the participants to develop self-enhancing practices, thereby they can refute their stigmatisation as inferior community members. These findings align well with previous research which suggest that deconstructing the stigmatisation of disability is crucial for promoting the empowerment of PWD (Balcazar & Suarez-Balcazar, 2017; Balcazar et al., 2012; McDonald et al., 2007).

In FPDB, the self-enhancement practices have particularly taken form in the collective activities, which allow its members to engage in socially oriented services. The findings of this study suggest that the wheelchair service centre has become an important site for manifesting the emphasis of FPDB to be a socially oriented organisation. All of the participants appear to highly value the wheelchair service centre as it creates opportunities for them to make contribution to their community by addressing the needs of those who are having difficulties with their mobility aids. There was a strong impression of pride and satisfaction when the participants were talking about the wheelchair service centre.

The participants seemed to show a similar impression of pride when they were recalling their participation in some community-based activities, notably their participation in the 2009 Independence Day Carnival. FPDB was the first disability organisation to participate in this very popular, annual community carnival. In addition, the participation in this carnival has often been recalled with a great fondness because of the particular story that was chosen to represent the identity of FPDB as a disability organisation. In this carnival, FPDB members were performing the story of *Punakawan*. The story of *Punakawan* (a famous Javanese mythology about four characters who symbolise wisdom and truth) was used to convey

FPDB's resistance against the common demeaning practices, which has equated disability with inferiority and incompetency. By presenting this story, this organisation wanted to communicate an understanding that everyone is equal and everyone can be a source of wisdom for others.

All of the participants evaluated positively such collective activities as these enable them to defy the common stigmatisation of PWD as useless, dependent and unproductive citizens. In other words, these activities have created possibilities for the participants to re-narrate their identity in ways that promote their personal and collective transformation (Cardillo, 2010; Mankowski & Rappaport, 2000; Rappaport, 1995, 2000, 2011; Rappaport & Simkins, 1991). One of the participants, Luna, illustrated such a transformation when she said that her involvement in FPDB has changed the way she sees herself, from viewing herself as a burden to describing herself as a confident, useful and aspiring community member. Another participant viewed his participation in FPDB as an opportunity to show to his community that PWD are talented and competent individuals. These reflections suggest that participating in this setting has enabled the participants to assert their positive identity as contributing community members. Such identity is particularly meaningful as it allows the participants to challenge the common, stigmatising portrayal of PWD as an object of pity.

Drawing on these findings, I concluded that the significance of FPDB as an empowering setting is related to its function as safe space for the participants to produce counter-narratives (i.e., stories, conversations, artworks) that challenge the dominant stigmatising portrayal of disability. As it has been identified in previous studies, the participants' experiences seem to highlight the potential of counter-narratives as a symbolic tool for marginalised individuals to make sense and alter their subjective realities (Cardillo, 2010; Case & Hunter, 2012; Hammack, 2008, 2011; Mankowski & Rappaport, 2000; Rappaport, 1995, 2000; Rappaport & Simkins, 1991). FPBD has become a vehicle for the

participants to express their version and experience of disability, which has been silenced and excluded from the mainstream understandings of disability. Such findings align well with past research which identifies empowering settings as a space where the marginalised are able to create and access alternative shared narratives that function as valuable symbolic resources for promoting positive identities, a sense of belonging and meaningful alliances (Cardillo, 2010; Case & Hunter, 2012; Mankowski & Rappaport, 2000; Rappaport, 1995;2000, 2011; Rappaport & Simkins, 1991). In other words, FPDB has functioned as an organisation where “a new community narrative is formed, people provide social and emotional support, and offer one another new ways to think and talk about themselves” (Rappaport, 1995, p. 804).

In FPDB, the idea of ‘being a contributing community member’ has become an important alternative shared narrative for the participants. All of the participants appeared to highly value the opportunities to engage in activities through which they can give back to their community. Such opportunities seem to play a key role in promoting the participants’ personal and collective liberation from the stigma imposed upon them. The idea of ‘being a contributing community member’ appears to be profoundly meaningful for the participants not only because such an identity enables them to resist their stigmatisation, but also because this identity embodies the participants’ personal beliefs and values.

Some of the participants have regarded their involvement in this organisation as a way to manifest their religious or spiritual belief (particularly in regards to the opportunities for taking part in socially-oriented practices). Informed by a particular teaching in their religious or spiritual belief, some of the participants explained that being a useful person for other people is an ideal way of being that they have been striving for. For these participants, FPDB has been considered as a meaningful medium to manifest such religious or spiritual belief.

Furthermore, the findings of this study also suggest that the participants’ appreciation on the socially oriented practices developed in FPDB is related to their personal values, which



are rooted in the Javanese worldviews. This point was particularly evident in Ilham's reflection, a participant who associated his involvement in FPDB with the notion of *Darma* as captured in the quotation used to entitle this section ("I am living my *Darma*"). Ilham viewed his involvement in this organisation as a manifestation of his *Darma* as a human being.

In the Javanese philosophy (i.e., Kejawen), the notion of *Darma* means duty or life task (Magnis-Suseno, 1997). According to the Javanese way of being, "everyone has his *Darma*, and the task of his lifetime is to bring it to completion ... It is expected that everyone will fulfil his or her *Darma* by contributing to public welfare, to maintenance of cosmic harmony" (Magnis-Suseno, 1997, p. 149). This understanding implies that the fulfilment of one's existential responsibility is not merely an individual process; rather it happens through the person's interdependence with his or her social ecology (Beatty, 1999; Koentjaraningrat, 1985; Guinness, 1986).

The emphasis on the interdependence between self and others has become a defining feature of Javanese social ethics (Beatty, 1999, Guinness, 1986; Koentjaraningrat, 1989). As noted by Koentjaraningrat (1989):

[One] must know that he can rely on his fellow human beings, especially on certain relatives, which imposes upon him the obligation to maintain good relations with them as well as with his close neighbours, to pay constant attention to their needs, share with them as much as possible, and constantly try to place himself in another person's situation (p. 457)

Some scholars have questioned the extent to which a sense of interdependence as described by Koentjaraningrat (1989) continues to be a significant feature of community life in contemporary Javanese villages (e.g., Antlov & Hellman, 2005; Hawkins, 1996; Newberry, 2005). Yet, the participants' experiences suggested the continuing relevance of maintaining interdependence as an ideal way of being in their social environment. Positive values associated with a sense of interdependence such as the value of *kekeluargaan* (ability to

maintain family-like relationships) appear to be an important point of reference for the participants to make sense of their experiences in this organisation.

Situated in such a cultural context, therefore, I concluded that the significance of FPDB as an empowering setting is related to its function as a social space where the participants can enact their cultural beliefs and values. The opportunities to articulate their identity as a contributing community member are not only politically but also culturally meaningful. Such identity entails a broader significance in relation to how the participants define and experience their sense of personhood. In other word, this organisation has created opportunities for the participants to fulfil and elaborate their idea of a meaningful existence, which are socio-culturally specific (Gemignani & Peña, 2008; Schwarz, 2014).

In conclusion, the findings of this current study support previous interpretations which conceptualise empowering settings as both a product of and a response to the socio-historical and cultural context in which the setting is located (Aber et al., 2011; Maton, 2008; Maton & Salem, 1995). How the participants experience and give meanings to FPDB as a transformative setting reflects the complex interconnection between the participants' subjectivity and their cultural ecology (McDonald, Raymaker & Gibbons, 2017; Seidman & Cappella, 2017). On the one hand, the participants' stigmatisation has been produced and sustained through cultural views and practices, which have positioned them as inferior others. On the other hand, through FPDB the participants have also created pathways to contest such stigmatisation by drawing on particular values and principles, which are grounded in their cultural ecology. In this sense, the participants' experiences in this organisation reflect how culture plays a key role in "the (re)production and contestation of inequality" (Reyes-Cruz & Sonn, 2011, p. 204).

In addition, the findings of this current study entails a particular understanding of how the notion of empowerment is experienced within the specific socio-cultural context in which

the participants live (Perkins & Zimmerman, 1995; Rappaport, 1987; Riger, 1993). Such findings are consistent with previous studies, which have underlined the importance of approaching the notion of empowerment as a contextual and ecologically specific construct (Aber et al., 2011; Maton & Salem, 1995; Perkins & Zimmerman, 1995; Rappaport, 1987, Riger, 1993; Seidman & Cappella, 2017). For instance, Riger (1993) questioned the extent to which “psychology’s traditional emphasis on agency, mastery and control” (p. 280) may generate relevant understandings of empowerment in a context where the image of empowered person is not primarily associated with the idea of individuation or individual mastery.

In the case of FPDB, the idea of ‘being a useful person for other’ appears to have a profound impact in generating a sense of empowerment among the participants. The participants’ reflections did suggest that a sense of agency, mastery and control have contributed in developing their sense of empowerment. Yet, the participants’ reflections also indicate that acquiring such criteria (i.e., a sense of agency, mastery and control) may not necessarily lead to the development of a sense of empowerment when they do not have the opportunities to extend their sense of connectedness and interdependence. For the participants, it appears that experiencing a sense of empowerment is not merely about asserting their identity as independent and rightful citizen. More than that, the participants seem to emphasise the importance of having meaningful connections with others in ways that resonate their cultural beliefs and values. For the participants, the idea of a meaningful connection entails the opportunities to be able to bring goodness for other people with whom they share their interactions with.

#### **9.4. Chapter Summary**

In this current study, I have examined the nature and dynamic of a local disability organisation as an empowering setting for its members. Taking the case of FPDB, I investigated the socio-psychological processes and mechanisms that have gradually developed this organisation as a transformative social setting, where its members can advance their struggle against ongoing discrimination and marginalisation imposed upon them.

The overall findings of this current study suggest the presence of collective practices that have enabled this organisation to function as both a transformative incubator and mindset changer for the participants. These collective practices (e.g., fostering emancipatory relationships, creating capacity building opportunities and promoting critical dialogues) are proactively developed and maintained, as a vehicle for the participants to gain essential capacities and resources, which include relational, instrumental and symbolic resources. The participants' access to these resources is central to develop their agency and solidarity as well as to promote their personal and collective acts of resistance.

Furthermore, I found that by having access to these resources, the participants have been able to create pathways through which they can tackle the psychological, political and cultural dimensions of their marginalisation. Psychologically, through their involvement in this organisation, the participants have been able to resist the psycho-emotional disablement that has sustained their marginalisation. Such a resistance involves a process of countering the internalisation of disabling mentalities as well as promoting positive self-definition, which allow them to refute the dominant, deficit-oriented representation of disability.

Politically, this organisation has created pathways through which the participants can counter the institutionalised marginalisation imposed upon them. By involving in FPDB, the participants have been able to engage in collective activities that allow them to challenge the

common patronising approaches used by government institutions in addressing disability issues.

Culturally, through their involvement in this setting, the participants have been able to disrupt the normalised stigmatisation of disability in their society. Participating in this organisation has created opportunities for the participants to engage in socially oriented practices that enable them to refute the stigmatisation of PWD as an object of pity and useless community members. The opportunities to engage in socially oriented practices have created a pathway for the participants to re-narrate their personal identity and to construct alternative shared narratives of disability in ways that reflect their ideas of a meaningful existence.

Lastly, the overall findings of this current study suggest that exploring the meanings and significance of FPDB as an empowering setting requires an ecological approach, which situates this organisation within the particular socio-historical and political context where it is located. How the participants experience and give meanings to this organisation is textured by the social and cultural milieus that have shaped the participants' subjectivity.

## **Chapter 10**

### **Conclusion and Implications**

#### **10.1. Conclusion**

Understanding pathways through which people may resist, disrupt or change oppressive systems and practices is a topic of concern that is central to community psychology (Bond, Serrano-García & Keys, 2017a; Nelson & Prilleltensky, 2010; Rappaport & Seidman, 2000). In line with such a concern, the current study investigated how participation in a local disability organisation may create a pathway through which people could collectively tackle the discriminatory systems and practices commonly imposed upon PWD in the Indonesian context. Drawing on the concept of empowering setting (e.g., Aber et al., 2011; Maton, 2008; Seidman & Capella, 2017) and the understanding of disability as a form of social oppression (e.g., Abberley, 1987; Mackelprang & Salsgiver, 2015), I examined the experiences of 18 members of FPDB, a local disability organisation in Yogyakarta Province, Indonesia. I particularly explored the socio-psychological processes and mechanisms that have enabled this organisation to function as an empowering setting, which amplifies the participants' struggle for equitable opportunities and living conditions.

In this thesis, I have presented two major findings that address the research question being explored in the current study. Firstly, I have explicated how disability as a form of social oppression has been experienced in the Indonesian context and how it has impacted negatively on the participants' living conditions. Secondly, I have illuminated how the participants have developed and utilised FPDB as an enabling social setting through which they can resist and transform their oppressive social realities.

Through this study, I have shown how disability in the Indonesian society has been generally constructed as a form of personal inferiority and how this has resulted in the multi-

dimensional disadvantages experienced by the participants. Psychologically, the construction of PWD as inferior others have challenged the participants through the normalisation of pathologising views toward PWD. Such a psychological challenge has evoked a pressure for the participants to internalise the disempowering mentality and attitudes imposed upon them. Politically, the dominant portrayal of PWD as defective individuals has exposed the participants to various forms of institutional marginalisation, which are operated through the continued reproductions of patronising social welfare policies and interventions. Culturally, the participants' marginalisation has been perpetuated by the common stigmatisation of PWD as pitiful, incompetent and useless community members.

Situated in such a socio-cultural and political context, I found that the potential of FPDB as an empowering setting centres on its ability to foster the participants' resistance against both the material and symbolic aspects of their marginalisation. Materially, this organisation has enabled the participants to address their social and economic disadvantages by providing them with relational and instrumental resources. As a result, the participants have been able to circumvent the challenging situations that have manifested and exacerbated their oppressive social realities, such as being socially isolated, having very limited working skills, and living in poverty. Through such findings I have demonstrated how this setting has functioned as a transformative incubator by promoting collective practices that enable the participants to develop meaningful social connections, accumulate knowledge and practical skills, as well as promote sustainable livelihoods.

Symbolically, this organisation has enabled the participants to develop and disseminate transformative understandings of disability that challenge the dominant construction of disability as a form of personal inferiority. The current study has unpacked how the participants have collectively created alternative shared narratives through which they can make sense of their experiences as well as re-narrate their identity in ways that

promote their agency and solidarity. In this setting, the development of alternative shared narratives has been specifically enacted through collective activities that allow the participants to make positive contributions to others and their community. Such opportunities have been highly valued by the participants as these enable them to embody their understandings of a meaningful existence, which are culturally specific. This point reveals how FPDB has operated as a mindset changer by generating new ways of thinking about disability, which then function as symbolic resources for the participants to counter the hegemonic, deficit-oriented narratives of disability.

Based on the overall findings summarised above, I proposed three points which demonstrate how this study has provided empirical evidence, which supports the existing literature on empowering settings, particularly in regard to how people resist and disrupt the construction of disability as a form of social oppression. Firstly, I concur with scholars who conceptualise empowering settings as a vehicle for marginalised individuals to disrupt or resist their oppression by generating resources and creating pathways for challenging the hegemonic systems and practices in their everyday life (e.g., Balcazar et al., 2012; Maton & Brodsky, 2011; Maton, 2008; Maton & Salem, 1995; Odahl-Ruan et al., 2015; Runswick-Cole & Goodley, 2013).

Furthermore, the findings of the current study also accord with previous research, which suggests that developing shared narratives in alternative settings can be a potential pathway through which marginalised individuals can contest and alter the frameworks of meanings that have underpinned and perpetuated their oppression (e.g., Hammack, 2008, 2011; Mankowski & Rappaport, 1995, 2000; Rappaport, 1995; 2000, 2011; Rappaport & Simkins, 1991; Salem, 2011). Through this study, I have provided an example of how a local disability organisation can act as an enabling vehicle by promoting alternative shared



narratives of disability that allow its participants to contest, negate and transform the dominant representation of PWD as inferior individuals.

Secondly, through this study I have underlined the argument, which views empowerment as a relational process (Christens, 2012; Keys et al., 2017; Rappaport, 1987; Zimmerman, 2000). At the individual level, the process of empowerment requires a quality of relationship that allows people to engage in emancipatory interactions with those they share similar history, experiences, values and aspirations. Such interactions may then enable people to reflect on and situate their own experiences in a broader context, which can promote the development of critical awareness (Case & Hunter, 2012; O'Donnell & Tharp, 2012; Zimmerman, 2000).

Critical awareness is the ability to understand the socio-cultural and political embeddedness of one's lived experience (Freire, 1996; Zimmerman, 2000). In regard to oppressive experiences, gaining critical awareness is crucial for enabling marginalised individuals to understand how the existing power structure has produced and sustained their subordination, therefore, allowing them to dispute victimization and self-blaming perspectives commonly imposed upon them (Case & Hunter, 2012; Montero, Sonn & Burton, 2017; Weis & Fine, 2012).

In line with these arguments, in this study I have found how a local disability organisation can function as a transformative site, by enabling the participants to gain critical awareness that allow them to politicise their understandings of disability. Such understandings have then become a catalyst for the participants to undo the internalisation of pathologising views and attributes commonly imposed upon them. In addition, I found that gaining critical awareness of disability has also encouraged the participants to exercise their political agency as rightful citizens. The participants' ability and courage to assert their political agency reflects a meaningful transformation because in the Indonesian political context people in

general have been accustomed to feel inferior due to the long history of political repression (Bebbington et al., 2006; Hadiwinata, 2004).

Thirdly, through the current study I have provided empirical evidence that explicates the role of settings as the mediating structures between the larger historical, cultural and political contexts and people's subjective experiences (Aber et al., 2011; Maton, 2008; Seidman & Cappella, 2017). As argued by a number of scholars, studying social settings may generate a deeper understanding of how contextual factors operate and shape people's life experiences, as well as how people enact their agency to negotiate with and modify the broader social structures (e.g., Aber et al., 2017; Campbell, 2014; Rappaport, 1995; Seidman & Capella, 2017). Such an understanding is particularly crucial for explicating how marginalisation and privilege are created, sustained, questioned, or challenged (Weis & Fine, 2012).

Consistent with these scholars, I have shown how a local disability organisation has become a potential site to understand the reciprocal interactions between the participants' subjective experiences and their larger socio-historical and cultural context. For instance, through this study I have been able to recognise how cultural factors might have contributed in perpetuating the participants' marginalisation. At the same time, this research also allows me to understand how the participants have drawn on their cultural reference to dispute and tackle their marginalisation.

In addition to the three points above, this study has also generated some insights, which reflect the particular context in which the setting is situated. In the following sections, I discuss how these insights may extend the existing arguments and assumptions on the role of empowering settings as a catalyst of social changes. Also, I outline the major theoretical, methodological and practical contributions of the current study.

## **10.2. Theoretical Contributions: The Importance of Contextual Understandings of Empowering Settings**

The importance of settings as both an area of research and foci of intervention has long been recognised and addressed in the field of community psychology (Aber et al., 2011; Cherniss & Deggan, 2000; Rappaport, 1995; Sarason, 1972; Seidman & Cappella, 2017). Yet, there remains a call for research, which explores the role of settings as a catalyst for social changes within more diverse contexts (Aber et al., 2011; Balcazar et al., 2012; Maton, 2008; Maton & Salem, 1995). Such studies are instrumental to develop more contextual theorisation of empowering settings as these may identify transformative elements or characteristics which are ecologically specific to particular types of settings (Maton & Salem, 1995). Through this thesis, I have contributed to addressing this call by generating a theoretical understanding of empowering settings, which is grounded on a particular socio-historical, cultural and political context.

In the current study, I have proposed an understanding of empowering settings which takes into account the complexity and the particularity of the broader ecological context in which the setting is situated. I have shown how the intersections between historical, cultural and political factors have shaped the way the participants experience and give meaning to FPDB as an enabling site. As a result, through this research, I have been able to identify the enabling elements which are unique to this setting. For instance, I have found that having the opportunities to engage in socially-oriented practices is a key element that enables the participants to experience their involvement in this organisation as a transformative journey. This element is ecologically specific as it is textured by and responds to the idea of a meaningful existence within the Javanese cultural context.

With such an ecologically specific finding, I have expanded the theorisation of empowerment in the field of community psychology that has been criticised for its limited

exploration on models of empowerment which are grounded in local and international contexts (Keys et al., 2017; Perkins & Zimmerman, 1995; Riger, 1993). As argued by Keys et al. (2017), analysis of empowerment is still mainly characterised with a focus on notions like self-efficacy, personal control and a sense of mastery which are not always applicable in various cultural contexts, therefore, such an analysis “fails to recognise that psychological empowerment involves person-environment fit” (p. 214). In this thesis, I have exemplified how a contextual research practice may generate an ecologically-specific meaning and understanding of empowerment.

By proposing a contextual theorisation of empowering settings, I have also contributed in addressing the calls “to integrate culture more fully into community psychology’s theory, research, and practice or action” (Kral et al., 2011, p. 46). Through this research, I have addressed this call by developing a culturally grounded interpretation of empowering settings. Through such an interpretation, I have enacted the premise of “context of diversity” which is central to community psychology (Trickett, 1996, p. 218). I have put the premise into practice by demonstrating an appreciation of the specific cultural context within which the participants of this study live.

More recently, Beehler and Trickett (2017) highlight the importance of developing situated and contextual knowledge to promote deeper understandings on how, “local culture and context affect the relevance, fit, appropriateness, and conduct of intervention” (p. 458). They particularly set their argument in response to the emerging evidence-based movement in psychology, which has been followed by an inclination toward the search for generalised and replicable models of interventions. They argue that community psychology needs to respond to this movement more critically considering its commitment toward developing situated and contextual knowledge and practices. In relation to the concept of empowerment, they draw attention on how the evidence-based movement may misdirect community psychology from

the understanding of empowerment as a situated practice, which is responsive to “the local definition of problems and solutions” (p. 460). Consistent with these arguments, in this study I have demonstrated how a local disability organisation has functioned as an empowering setting by cultivating transformative practices, which are responsive to the ecological context in which this setting is situated.

Lastly, by focusing on a local disability organisation as the site of study, I have contributed in expanding the connection between community psychology and disability study, which have remained limited (Balcazar & Suarez-Balcazar, 2017; Goodley & Lawthom, 2005; McDonald et al., 2017). In the current study, I have particularly presented a theoretical interpretation that may explain the socio-psychological pathways through which a locally based disability organisation can function as an enabling social setting for its members. Through such a theorisation I have contributed in addressing the limited research in community psychology that investigated the nature and dynamic of disability as a form of social oppression, how it affects both PWD and non-disabled people, as well as how it can be disrupted and changed (Balcazar & Suarez-Balcazar, 2017; McDonald et al., 2017).

Particularly in the Indonesian context, in this study I have contributed by addressing the scarcity of disability studies which portray and amplify the agency of PWD in advocating their struggle for equitable opportunities and living conditions (Adioetomo et al., 2014; Yulianto, 2011). While the emerging disability movement in Indonesia has generated an interest in understanding the nature and dynamic of local disability organisations as a form of political action, little is known about the socio-psychological aspects that enable such organisations to function as a transformative site for its members (Yulianto, 2011). In this regard, I have made a relevant contribution by addressing the gap in the disability studies in Indonesia.

### **10.3. Methodological Contributions: An Enactment of Contextual Research Practice**

Consistent with its focus on ecological perspectives of human behaviours, community psychology is oriented toward research methodologies which may “provide a highly nuanced and contextualised description of a phenomenon that illuminates the interweaving of context, culture and diversity” (Case, Todd & Kral, 2014, p. 62). Such an orientation is rooted in community psychology’s inclination toward contextual philosophy of science. This philosophy assumes that “knowledge is time and place dependent” (Beehler & Trickett, 2017, p. 469). Drawing on this assumption, community psychology views that human functioning does not operate in a social vacuum, rather it is directed by the transactions between individuals and their socio-ecological context (Kelly, 1969; Trickett, 1996, 2009, 2015). Therefore, there has been a call in community psychology to generate research practices, which are responsive to the socio-historical and cultural landscapes in which the phenomenon under study is situated (Trickett, 2009).

Throughout this thesis I have addressed this call by demonstrating how an orientation toward a contextualist philosophy of science was put into practice. In my experience, conducting culturally contextual research involved a process of examining how the issues of disability have been culturally and politically constructed in the Indonesian society. Particularly, such an examination required me to be sensitive to the historical settings that have shaped the nature of community life in the Javanese villages where the research participants live. As a result, I have been able to interpret the participants’ experiences more accurately by linking their subjective meanings and reflections with the multiple social realities that have shaped their living conditions (Bond, Serrano-Gracia, Keys, 2017b; Gemignani & Peña, 2008).

The other methodological contribution presented in this study is related with the use of constructivist grounded theory (CGT) as the research method (Charmaz, 2000; 2007; 2009). I

have exemplified that the use of CGT may extend the implementation of transformative paradigm in disability research (Mertens et al., 2011). As a consequence of adopting the transformative paradigm in disability research, I have opted for methodological frameworks that are sensitive to the issues of social justice, cultural respects and reciprocity (Mertens et al., 2011). These are all essential issues to ensure that research processes will be conducted in a manner that respects and supports the struggle of PWD for equal rights, treatments and recognition, therefore, preventing the reproductions of discrimination and marginalisation commonly imposed upon PWD (Moore et al., 1998; Mertens et al., 2011).

While providing an ethical, ontological and epistemological framework for this thesis, the transformative paradigm in disability research does not necessarily outline specific sets of data collection and analysis methods, which can adequately translate the recommended ethical positioning (Mertens et al., 2011). As argued by Moore et al. (1998), literature on disability studies has tended to focus on examining what “good disability research is *not* like” [emphasised in original], but fewer references have explored how to enact the characteristics of critical disability study (p. 14). Throughout this study, I have addressed this gap by demonstrating how CGT may serve as an appropriate method to put into practice the transformative paradigm in disability research. I outline the compatibility of CGT and the transformative paradigm in disability research in the following two points.

Firstly, I found that CGT is compatible with this paradigm because it enabled me to prioritise the voice and local knowledge of PWD in the research process. CGT inclines toward data collection methods that enable the participants to share their subjective understandings and experiences of the phenomenon through co-constructive conversations with the researcher (Charmaz, 2006). Therefore, employing CGT has enabled me to collect data in a non-directive manner, which in turn creates a dialogical atmosphere for the participants to express their voices with minimum filtering (Allen, 2011).

Furthermore, CGT has also allowed me to analyse the data inductively, without applying preconceived concepts or theories to code and interpret the participants' experiences. By applying such an analysis, the participants' voice and knowledge have directed how the theoretical interpretations were developed in this study. In addition, through the process of member checking, I have created possibilities for the participants to provide their feedback on the data analysis results. This process has enabled me to increase the efficacy of my theoretical interpretations, by ensuring these interpretations have accurately portrayed the participants' voices and knowledge. These practices are in line with the transformative paradigm in disability research, which opts for models of research that enable PWD to extend their control and agency in knowledge production (Mertens et al., 2011).

Secondly, throughout this thesis I have demonstrated that by combining CGT (Charmaz, 2000, 2007, 2009) and the transformative paradigm in disability research (Mertens et al., 2011), I was able to attend more fully to the issue of critical reflexivity in research practice. CGT provides relevant data collection and analysis methods that enabled me to engage critically with my subjectivities and how these may impact on the research process. Furthermore, by adopting the transformative paradigm in disability research, I was also enabled to critically reflect on the issues of power and privilege in knowledge production. Informed by this paradigm, I found that applying a reflective approach to research involved deliberate actions to conduct the study in ways that were responsive to the participants' worldviews and way of being. This kind of reflexivity is crucial to promote trust and avoid patronising research relations (Mertens et al., 2011). An example of such actions was my decisions to modify the interview schedule to accommodate issues and concerns raised by the participants.

In the context of disability studies, critical reflexivity is particularly related to the process of recognising one's own presumptions, attitudes and positioning toward disability



(Moore, 1998). Such awareness allows researchers to identify how their own views and prior knowledge of disability may impact upon the research process. Maintaining critical reflexivity is crucial in disability studies to prevent the reproduction of disabling practices against PWD as a result of the researchers being unaware of their prejudicial thoughts and attitudes toward disability (Moore et al., 1998; Tregaskis & Goodley, 2005; Tregaskis, 2004).

In this thesis, I have shown that adopting CGT has enabled me to address the issue of critical reflexivity, particularly through the practices of memo writing. As suggested by Charmaz (2006) memo writing is a process in which I documented my thoughts, reactions and reflections that emerged throughout the data collection and analysis process. I found that such a practice helped me to be more aware of how I might have unintentionally reproduced prejudicial attitudes toward PWD through the way I respond to and interpret the research participants' views and experiences.

In conclusion, in line with previous literature on culture and psychology, I found that adopting a contextual approach to research and employing CGT have enabled me to develop a situated and reflective work that connects the participants' experiences with their larger socio-historical and cultural world (Reyes-Cruz & Sonn, 2011). Furthermore, such an approach has also been instrumental in generating knowledge that may amplify the participants' voices, agency and struggle for liberation

#### **10.4. Practical Implications: Working with Local Disability Organisations in the Indonesian Context**

Drawing on the participants' experiences, particularly in regard to how they have developed and envisaged FPDB, I propose three major practical implications as follows:

#### **10.4.1. Implications for practitioners and agencies working in the disability sectors in the Indonesian context.**

The overall findings of this study have demonstrated the importance of FPDB as a vehicle for the participants to assert their agency and determination in resisting the socio-psychological, institutional and cultural marginalisation imposed upon them. For practitioners and agencies working in the disability sectors, such findings underline the importance of working toward models of practices that allow PWD to have control over the design, implementation and evaluation of the program being delivered.

In addition, this present study also highlights the need for practitioners and agencies to have adequate understandings of the historical, political and cultural factors that have shaped the challenging living conditions of many PWD in Indonesia. Developing practices based on situated and ecologically contextual understandings of disability are crucial for preventing the reproduction of victim-blaming types of interventions.

#### **10.4.2. Implications for agencies managing CBR programs.**

As explained earlier in this thesis, FPDB is a locally initiated disability organisation that was established as part of a CBR program implemented in the villages where FPDB members come from. In a CBR program, locally initiated disability organisations are generally expected to have a leading role by functioning as an advocacy group for PWD in the targeted locality (Deepak et al., 2013; WHO, 2002). Therefore, the implementation of a CBR program usually involves conscientious efforts, which are aimed at supporting the development and sustainability of local disability organisations (Deepak et al., 2013; WHO, 2002).

By explicating the meanings and significance of a local disability organisation from the vantage point of its participants, this study has identified some organisational

characteristics and practices (e.g., promoting emancipatory relationships, facilitating capacity building, cultivating critical awareness) that contribute positively to maintaining people's active involvement in such an organisation. Promoting the development of these characteristics and practices may become a pathway through which related agencies can support the development and sustainability of local disability organisations.

#### **10.4.3. Implications for FPDB.**

Despite its strength and potential as a transformative setting, this study reveals that FPDB as an organisation has been challenged by some organisational issues that may risk its sustainability if these issues are not adequately addressed. Leadership was one the challenging issues that was frequently raised by the participants. Both the participants' reflection and my observation during the fieldwork, suggested the presence of a dilemmatic situation in regard to leadership issues in FPDB.

The current leaders were highly admired by all of the participants for their personal charisma and their ability to reach, connect with, inspire and encourage every FPDB member. While the presence of such leaders has contributed positively in developing and sustaining FPDB as a relational community, the participants' reflections suggest that this style of leadership has also created a sense of vulnerability. The participants seemed to believe that the sustainability of FPDB is most likely determined by the willingness of these particular individuals to continue their role as the organisation leaders. Therefore, there is a shared concern among the participants about the future of the organisation if there is any situation that will prevent the current leaders to continue their role.

Furthermore, this leadership issue has also generated a particular challenge for those who are in the leadership position. Through my conversations with these individuals, I learned that the expectation for them to continue the leadership role has sometimes become a

source of personal distress. As they have been in the leadership role since the organisation was established, they expect that other members will replace their position. Yet, all of FPDB members seemed to view that no one is good enough to replace them. One of the leaders mentioned that the demand to continue the leadership has sometimes made him experience burnout. Such a finding implies the need for FPDB to address this leadership issue to ensure its sustainability. Proactive and systemic efforts are needed to promote leadership regeneration in this organisation.

This kind of leadership challenge is hardly unique to FPDB. Newly initiated alternative settings generally share a similar dilemma (Cherniss & Deegan, 2000; Sarason, 1972). Charismatic individuals usually become the key actor behind the emergence of an alternative setting. The challenge then is to ensure the transition of leadership, so that the sustainability of the setting is not centred on particular individuals (Maton & Salem, 1995). Such an observation suggests that working together with newly initiated local disability organisations to manage their leadership issues may become a potential area where related practitioners and agencies can make their contributions.

### **10.5. Limitations and Implications for Future Research**

Employing a qualitative approach to research, the current study has been able to provide a detailed, contextual and nuanced account of the phenomenon being studied. Yet, the utilisation of this approach has also limited the generalisations of the findings, due to the particularity of the setting and the small number of participants. More research, which is conducted in similar settings, is required to generate richer discussions on empowering characteristics, processes and mechanisms that are consistent across contexts.

Despite my conscientious attempts to conduct a study that promoted equal relationships and a collaborative approach with the participants, I have clearly held more

control in developing the course of the study. For instance, the participants did have opportunities to convey their feedbacks on the data analysis result, but they were barely involved in the data analysis process. Future research on local disability organisations, which more rigorously employing participatory approach, is highly needed to extend the meanings and significance of knowledge production as an empowering process. Through such research, the participants may have greater control in identifying and deciding topics of research, which matter most for their organisations, as well as, to influence the research process in ways that will benefit them most.

In this thesis, I have extensively examined the strengths and potential of FPDB as a transformative setting for its members. However, I have developed little explorations and discussions on the limitations and challenges of FPDB as an organisation. Some of the limitations and challenges identified by the participants are leadership and managerial issues. For instance, some participants expressed their preference for the informal approach commonly used in FPDB to manage their collective activities. Yet, some raised a concern about the lack of clarity and responsibility in how collective tasks have been distributed and executed. Such an observation implies the need for long-term collaborative action research, which may enable the researcher to work together with FPDB members to develop strategies for addressing the limitations and challenges found in the organisation. Conducting such a long-term collaborative research may also generate fuller understandings about the gradual evolution of this organisation as an empowering setting and how it extends its transformative effects to broader levels.

As an academic engaging in a disability research in the Indonesian context, I have had the opportunity to learn about a range of challenges and possibilities in conducting a study, which is aimed at amplifying the struggle of PWD for equality, social justice and dignity. These include the challenges in navigating my position as a non-disabled person as well as

my position as an academic, which has afforded me with particular privileges that most of the research participants do not have. However, I have not been able to fully explore these issues in this thesis. Developing future research which further investigate such issues may generate relevant information for other researchers who chose to pursue disability studies in the Indonesian context.

In conclusion, throughout this dissertation I have highlighted the meanings and significance of a local disability organisation as an empowering setting in the Indonesian context. Particularly, I have explicated the transformative socio-psychological processes and mechanisms that have characterised such an organisation. Documenting, disseminating and amplifying the story of the research participants and their journey to empowerment is timely crucial because discrimination and marginalisation of PWD are still pervasively normalised in the Indonesian society. Furthermore, concerted efforts and solidarity are highly needed to support the newly emerging critical disability movement in the country. Thus, the study limitations outlined in this section pose a call and possibilities for me as an Indonesian-based community psychologist to further develop theoretical and practical contributions that may amplify the struggle of the Indonesian disability movement for an equal and just society.

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## **Appendix 1: Plain Language Statement**

# **INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH**

### **You are invited to participate**

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You are invited to participate in a research project entitled “A Case Study of Participation in A Community Based Rehabilitation Program in Bantul District, Yogyakarta, Indonesia”

This project is being conducted by a student researcher Monica E. Madyaningrum as part of a PhD study at Victoria University under the supervision of Dr. Christopher Sonn and Dr. Adrian Fisher, from the College of Arts, Victoria University

### **Project explanation**

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This study aims to investigate community members’ perceptions and experiences with community participation, particularly related with a community based rehabilitation program taking place in villages in Bantul District Yogyakarta. The study will target both of those who are directly and indirectly linked to the program. Using qualitative approach (e.g., interviews), this study seeks to understand the meanings, the practices and the significance of participating in a community program from the perspective of community members.

It is expected that the study can provide insights needed to better understand contextual approaches to community participation that meet the community members’ aspirations and expectations. This kind of understanding is deemed necessary as community participations in community development programs have been examined mainly from the perspectives of those holding administrative roles (e.g., local government officers, NGO staffs). Rarely included are the reflections of the community members’ themselves about their involvements.

### **What will I be asked to do?**

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Participants will be requested to answers questions from the researcher and the information provided will be confidential. Only the researcher and her supervisors will know who have been interviewed. Questions asked throughout the course of the interview will be about your experiences, thoughts and expectations of community participations, particularly related with a community based rehabilitation program taking place in villages in Bantul District Yogyakarta.

The interview will be conducted by the researcher at time and place suitable to you and will be recorded with your permission. Each interview will take 60-90 minutes. The data will later be transcribed, but any identifying information will be removed.

### **What will I gain from participating?**

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By participating in this research, you will have an opportunity to share your experiences, thoughts and expectations of community participations. Your knowledge will be useful to better develop the practices of community participation in your locality as well as in other localities embedded in the similar kind of socio-historical and political contexts.

### **How will the information I give be used?**

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The information will be presented in a dissertation manuscript and will be available in academic publications. However, no identifying details from the participants will appear in any of those documents.

### **What are the potential risks of participating in this project?**

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Participants may feel uncomfortable with some of the questions asked. However, participants can stop the interview at any time should they feel uncomfortable with the questions. Participants can also withdraw from the research when they feel uncomfortable to continue. Should participation in the research is psychologically harming the participants, the researcher will facilitate them to access free assistances from a psychological service center namely Pusat Pelayanan Tes dan Konsultasi Psikologi (P2TKP) in Sanata Dharma University, Yogyakarta.

### **How will this project be conducted?**

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All the interviews will be semi-structured and audio-recorded. Participants will be asked to express their agreement to participate in this research at the beginning of the interview. The interviews will be conducted in a location convenient for the participants.

### **Who is conducting the study?**

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#### Chief Investigator:

Dr. Christopher Sonn  
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Phone: +61 3 9919 5226  
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#### Associate Investigator:

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Monica E. Madyaningrum  
College of Arts – Victoria University  
Phone: +61 416 534 588  
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Any queries about your participation in this project may be directed to the Chief Investigator listed above.

If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email [researchethics@vu.edu.au](mailto:researchethics@vu.edu.au) or phone (03) 9919 4781 or 4461.

## Appendix 2: Consent Form

# CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

### INFORMATION TO PARTICIPANTS:

We would like to invite you to be a part of a study entitled “A Case Study of Participation in A Community Based Rehabilitation Program in Bantul District, Yogyakarta, Indonesia”. Questions asked throughout the course of the interview will be about your experiences, thoughts and expectations of community participations, particularly related with a community based rehabilitation program taking place in villages in Bantul District Yogyakarta.

You will be requested to answers questions from the researcher and the information provided will be confidential. Only the researcher and her supervisors will know who have been interviewed. The interview will be conducted by the researcher at time and place suitable to you and will be recorded with your permission. The information will be presented in a dissertation manuscript and will be available in academic publications. However, no identifying details from the participants will appear in any of those documents.

You may feel uncomfortable with some of the questions asked. However, you can request that the interview or the recording of the interview to be stopped stop at any time. The interview will be continued only with your permission. Should you feel uncomfortable to continue your participation, you can also withdraw from the research. The researcher will also help you to access any necessary assistance, should you become distress or unwell during the course of the research.

### CERTIFICATION BY SUBJECT

I, \_\_\_\_\_

of \_\_\_\_\_

certify that I am at least 18 years old\* and that I am voluntarily giving my consent to participate in the study:

“A Case Study of Participation in A Community Based Rehabilitation Program in Bantul District, Yogyakarta, Indonesia” being conducted at Victoria University by:

Dr. Christopher Sonn

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by:

Monica Madyaningrum

and that I freely consent to participation involving the below mentioned procedures:

- interview

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed:

Date:

Any queries about your participation in this project may be directed to the researcher

Dr. Christopher Sonn  
College of Arts – Victoria University  
Phone: +61 3 9919 5226  
Email: christopher.sonn@vu.edu.au

If you have any queries or complaints about the way you have been treated, you may contact the Ethics Secretary, Victoria University Human Research Ethics Committee, Office for Research, Victoria University, PO Box 14428, Melbourne, VIC, 8001, email [Researchethics@vu.edu.au](mailto:Researchethics@vu.edu.au) or phone (03) 9919 4781 or 4461.

**[\*please note: Where the participant/s are aged under 18, separate parental consent is required; where the participant/s are unable to answer for themselves due to mental illness or disability, parental or guardian consent may be required.]**



## **Appendix 3: Interview Schedule (FPDB Members)**

### **Interview Schedule for FPDB Members**

#### **Introduction**

I am conducting a study that aims to investigate local people's experience with the CBR program that was implemented in this village. I am talking to different people to understand their experiences and feelings about their involvement in this program. In relation to this study, I particularly would like to understand your experiences with FPDB as a local disability organisation that has become a key actor in the implementation of the program. I would like to have a conversation with you about your involvement in this organisation and what does it mean for you.

So, thank you for your willingness to participate in this study. Before we start, I just like to remind you that anything you share with me will be totally confidential. I hope this will help you feeling more comfortable to openly share any thought or comment that you have. Also, please feel free to let me know if you like to stop our conversation at any point, or if there is any particular information that needs to be treated with certain considerations.

If you feel comfortable with it, I would like to record our conversation to help me compile the information more accurately.

#### **Key Questions**

1. The interviewee's profile
  - a. Daily activities
  - b. Social participation other than in FPDB
2. Participation in FPDB
  - a. Initial involvement in FPDB
    - How did you become involve in FPDB?
    - When was it?
    - Were you at that time involved in other organisation?
    - How did you know about FPDB?
    - What was interested you to participate in FPDB?
  - b. Current involvement in FPDB
    - In what ways do you participate in FPDB? What are the activities that you are involved in?
    - How long you have been involved in these activities? Have you take part in these activities since you joined FPDB for the first time?
    - What do you like about being part of these activities?
  - c. Meanings of participating in FPDB
    - Overall, what do you like about participating in FPDB? What do you find as the advantages of joining of this organisation? What do you enjoy most about being part of it?
    - What is it that drives you to maintain your involvement in FPDB up until now?

- How does participate in FPDB affect you personally? Does it bring any personal change? In what ways, does participating in FPDB bring personal changes?
  - To what extent do you think, you share similar views with other FPDB members in terms of how participating in this organisation may affect you personally?
- d. Views on FPDB
- In your understanding, what are the aims of this organisation?
  - To what extent do you think that FPDB has been able to meet its aims?
  - What do you find as the strengths of FPDB? In your opinion, is there any distinctiveness that make this organisation differs from the other disability organisations that you know?
  - How do you find FPDB has changed from its beginning to now?
  - What do you find as important events that had meaningful effects on the development of FPDB? What do you think as the important milestones for this organisation?
  - What do you think as the current challenges of FPDB? Have these challenges been recognised and addressed in this organisation? Do you identify any situation that you would like to change about this organisation? Why is it so?
  - Do you have any experience of inviting or supporting friends to join FPDB? What was motivated you to do so? How did they respond to your invitation?
- e. Future aspirations for FPDB
- What are your future aspirations for FPDB? How do you like to see FPDB in the future? Why do you like it so?
  - What do you find as the strengths of FPDB that will enable this organisation to meet the aspiration you described? Do you identify any challenge that may limit the ability of this organisation to meet such an aspiration?
3. Disability issues in general and views on the CBR program
- a. What does living with disability mean in this community? What are the challenges that are commonly experienced by *difabel* people? How do people generally overcome these challenges?
  - b. How do people generally respond to or treat *difabel* people in their everyday interactions?
  - c. What are your thoughts on the implementation of the CBR program that is intended to make this community becomes more inclusive in which *difabel* people can enjoy equal opportunities and living conditions?
  - d. What aspects of your community that you would like to change in relation to the attempt of making this community become more inclusive for *difabel* people?

### Closing

Well that is all from me. Before we end it, do you have any question or concern that you like to discuss?

## Appendix 4: Interview Schedule (KARINAKAS staff & Community Members)

### Interview Schedule for KARINAKAS staff & Community Members

#### Introduction

I am conducting a study that aims to investigate local people's experience with the CBR program that was implemented in this village. I am talking to different people to understand their experiences and feelings about their involvement in this program. In relation to this study, I would like to have a conversation with you about your involvement in this program and also about disability issues in this community.

So, thank you for your willingness to participate in this study. Before we start, I just like to remind you that anything you share with me will be totally confidential. I hope this will help you feeling more comfortable to openly share any thought or comment that you have. Also, please feel free to let me know if you like to stop our conversation at any point, or if there is any particular information that needs to be treated with certain considerations.

If you feel comfortable with it, I would like to record our conversation to help me compile the information more accurately.

#### Key Questions

1. Disability issues in the community
  - a. What does living with disability means in this community? What are the challenges that are commonly experienced by *difabel* people? How do people generally overcome these challenges?
  - b. How do people generally respond to or treat *difabel* people in their everyday interactions?
  - c. What are your thoughts on the idea of making this community becomes more inclusive in which *difabel* people can enjoy equal opportunities and living conditions?
  - d. What aspects of your community that you would like to change in relation to the idea of making this community become more inclusive for *difabel* people?
2. The CBR program
  - a. What is your role in this program? How did you become involved in this program? What do you like about being part of this program?
  - b. In your understanding, what was the background for the development of this program? What are the aims of this program?
  - c. In your opinion, to what extent that this program has meet its aims?
  - d. How do you think this program has affected the targeted community? What do you identify as the positive outcomes of this program?
  - e. What do you find as the challenges for implementing this program?

#### Closing

Well that is all from me. Before we end it, do you have any question or concern that you like to discuss?