

CONTESTING CONCEPTIONS OF DISABILITY IN JAVANESE SOCIETY AFTER  
THE SUHARTO REGIME: THE CASE OF YOGYAKARTA, INDONESIA

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## ABSTRACT

This study explores the contesting concepts of disability Javanese people in Yogyakarta Indonesia. Using Pierre Bourdieu's theory on *habitus*, field, and capital; it finds that there are four concepts of disability in Javanese society at Yogyakarta, i.e. traditional Javanese conception, Islamic conception, medical model conception, and social model conception. Javanese concept perceives disability as magic, Islamic concept believes disability as an object of charity, medical model looks at disability as an abnormality, and social model conceptualizes disability as a "social construction". Those concepts are contesting each other which could strongly be seen from health and educational policies as well as public facilities. Based on those policies, the study finds that medical model is the dominant concept.

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## CHAPTER I

### INTRODUCTION

In Indonesia, people with disabilities are only rarely involved in academics, particularly in fields relating to the social sciences. In both the mainstream and academic press, there is barely any serious discussion on disabilities among Indonesians. Indeed, people with disabilities have been forgotten almost entirely by Indonesian scholars. This scarcity of the disabled in Indonesian academic discourse parallels their social exclusion across most of Indonesia. Most such individuals live without government aid, without assistive technology or support, and without even public awareness. Nonetheless, according to the World Health Organization, the population of disabled people in Indonesia is approximately 20 million people (Cheshire, 2010).

Ninety-eight percent of the 1.8 million children in Indonesia who have disabilities do not receive educational services (*Kedaulatan Rakyat*, 3, 2008). Most of their educational opportunities are in special schools that specifically cater to students with disabilities. Due to the lack of public awareness of disabilities, especially in government circles, as well as the national and municipal budgets set aside for providing employment, public access and appropriate education for these people in need, it is clear that the Indonesian government is not capable of providing accessibility and assistive technology necessary to integrate the disabled into mainstream society. Thus, many of these children become beggars and street singers, often found in public places, bus stations and traditional markets.

On the other hand, socio-cultural perceptions and stereotypes determine the treatment of the disabled in daily life across society; as such perceptions and popular images of the disabled perpetuate their poor living conditions. The disabled in Javanese society, however, has been traditionally considered as people who have supernatural powers and, therefore, are to be respected. Public attitudes toward them in modern Indonesia, as well as governmental policies, nonetheless favor the able-bodied citizens.

The Indonesian government inherited the Dutch policy and modern perception of people with disabilities as “abnormal” or “social deviants.” Under the authoritarian Suharto regime, people with disabilities were categorized on the basis of medical diagnoses and then relocated to specified schools or institutions. Thus, they became recipients of charity without any policies or conditions concerning such charity, a status quo that derived from the colonial legacy of modern medical practice brought to Indonesia by the Dutch. Currently, many educational institutions and workplaces stipulate that applicants must meet standards for mental and physical health (*sehat jasmani rohani*) before admission. Such a policy segregates those with disabilities, preventing them from receiving an education and working as able-bodied people.

In addition to general social discrimination, Islam has also exerted an influence on traditional, negative perceptions of disability in Javanese daily life. Islam is one of the main religions in Yogyakarta. For Muslims in Indonesia, people with disabilities are people who should be given special treatment, since Islamic tenets state that they should be respected. Nonetheless, disabled positions are dependent upon able-bodied people for such help. As a consequence, people with disabilities are seen as objects of charity,

due to the belief that people with disabilities are weak, and in Javanese society it is typically believed that these people should be helped. Thus, they become the responsibility of philanthropic organizations. Many charities advocate for aid for the disabled using religious ideas, chief among which are those found in Islam, the most dominant religion in Indonesia (Thohari 2008: 167-210 in Susanto 2008).

In the 1990s, several non-governmental organizations (NGOs) in Indonesia developed a new characterization for disability, conceiving it as a “social construction.” These groups attempted to establish a more inclusive society for people with disabilities by struggling to implement equitable conditions and equal rights for people with disabilities at all levels of society. They have advocated accessibility for public services, inclusive education that does not segregate those with disabilities from the non-disabled, as well as increased awareness and protection of the rights of people with disabilities as equal members of society.

In 1998, Indonesia made a remarkable transition to a democratic political system, after 32 years of Suharto’s authoritarian regime. At this point, many groups and social organizations took advantage the moment to raise their concerns, including the disabled rights’ movement in Yogyakarta. Unlike the period during Suharto’s regime, in the reform era they had the opportunity and space to argue and promote new ideas. One of these paradigms was advocacy for use of the label “difabel,” which means “differently-abled-people,” as opposed to “disabled people”. These groups believed that the term “disabled” itself forms an inherently discriminatory category, since “dis” refers to “cannot,” or the inability to do something. These organizations believe that everybody

has their own different abilities. The struggle to change the term actually means working to form a new concept, which demands new policies, and attitudes have as a result become more sensitive toward people with disabilities within Indonesian society.

However, since socio-cultural conceptions and social stereotypes of disability can significantly determine the legal definition of disability, in many cases, the activities of such civil advocacy groups have clashed with government policies. This has contributed to public perception that certain policies or government programs are not working well. Moreover, many efforts to implement equal rights for people with disabilities have not yet met with success. As social attitudes have changed more rapidly than government norms, the beliefs of Javanese people concerning disability are no longer congruent with the implementation of programs related to disability rights.

This surprising condition is what first triggered my belief that there are many conceptions of disability in Indonesia, as well as my recognition of the significance for academic study on the concept of disability in Indonesian society. I believe that this research will be directly useful for both the academic world, since it reports on a sector of the population that is little understood among researchers. Moreover, this study will contribute to the establishment of a basic definition of disability and a paradigm for policy makers and activists who work toward implementation of equal rights for people with disabilities.

Hence, this research traces differing conceptions of disability among the Javanese, which is the biggest ethnic group in Indonesia and one of the most significant cultures, as it determines the direction and tenor of Indonesian society in many aspects.

It will explore the contesting views toward disability as well as the implications of such opposing ideas within Javanese society in Yogyakarta, Indonesia.

Yogyakarta is an important city in Java. It is the only province in Indonesia ruled by a traditional government of a Javanese Kingdom. Moreover, studying Javanese society in Yogyakarta is appropriate since it is the most significant city within this society. In addition, Yogyakarta stands out as having instituted a pilot project in the 1990s to make a name for itself as the most accessible city for disabled people in Indonesia. It also has the strongest disabled rights movement among all cities in the country, as well as a variety of conceptions regarding disability. Thus it is a fecund source for contesting concepts for disability in Javanese society.

### **Literature Review**

Regarding the concept of disability, for many years, it has been perceived as a medical issue according to a medical model of individuals that Michael Oliver (1990) describes it as being based in ‘personal tragedy theory,’ whereby people with disabilities are seen as having impairments of one form or another. Therefore, they are not able to perform any type of work that non-disabled people normally undertake, or they may take part in kind of activities in a limited way without having the capability to do certain tasks.

This conception of disability can be derived from Talcott Parsons’s principle encouraging that, at the inception of an illness or affliction, a patient should take on what he calls a sick role. Based on the assumption that disease and illnesses responsible for mediating an individual’s physiological and psychological abilities (Barnes, 1990; Oliver, 1990), a key element of this medical approach is that it advocates perceiving people with



disabilities in deference to the doctor, as the expert authority, who ‘objectively’ treats the symptoms of the disease in order to cure the patient, thereby regaining his or her former status as a ‘normal’ person (Parsons, 1951). However, within this model, the treatment of people with disabilities is focused on impairment, classifying the varieties of disablement and, of course, navigating toward a clear resolution of the problem.

Parsons’ point in his argument on sickness is that society is a system which aims to keep its equilibrium and, in this sense, sickness as a social deviance. Illness is perceived as the breakdown of the general ‘capacity for the effective performance of valued tasks’ (Parsons 1964: 262). Loss of such capacity interrupts one’s loyalty to commitments in specific contexts, such as the family or workplace. The cause of this disloyalty is not due to disregard of a society’s social norms, but rather one’s inability to adapt to them (Parsons, 1964: 270). Moreover, to cure and regain one’s normal condition is equivalent to putting them back into society. Within this view, disability is further framed as having been caused by an abnormality belonging to a person and his or her inability to perform a task.

The WHO (World Health Organization) adopts this model in its approach toward perception of people with disabilities, through ICDH (International Classification of Impairment Disability and Health), WHO intends to classify such conditions. Disability is defined as “any restriction or lack (resulting from the impairment) of ability to perform an activity in the manner or within the range consider normal for a human being” (Edward, 2005). The proponents of the ICDH classification have said that it has proven

to be very useful in many fields, such as social security, health care, welfare, health statistics, social service delivery, and so forth.

This model has also been widely adopted around the world, both in academic fields and in government policies. Many countries have adopted it as the basic principle to treat people with disabilities. In the Netherlands, Germany and Scotland, it is used to determine one's work capacity because of impairment. Among academics, it has become the basic principle for the medical model, which was until recently the sole dominant approach in disability studies (Pfeiffer, 2000: 503).

The social model was a pioneer approach in its criticism of the medical model. The work of disabled people and scholars in Great Britain, such as Vic Finkelstein (1993), Michel Oliver (1990; 1996), and Colin Barnes (1990), led to new insights in developing the social model for disability studies. The outset of the development of model of disability studies was from the 1970s to the 1980s. These academics developed the argument that people with disabilities, based on their life experiences including social and physical barriers to full citizenship, are a minority social group, oppressed by society. Disability is socially created and socially constructed; thus, it is not just a personal tragedy.

The social model emerged in reaction against the medical model, which was dominant in disability studies and other related disciplines. This model seek to reduce the disability to a concept of impairment, so that disability can be placed within the mind or body of an individual rather than an external authority that defines, analyzes, controls,

and treats those with disabilities, namely, professional doctors (Oliver, 1996: 37; Humphrey, 2000: 63).

Disability, as Oliver defines the term, is to be seen as “social oppression”, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance” (Oliver, 1996: 1). According to the social model, disability is understood as something imposed on people with disabilities, on the top of their impairments, and such further disablement is enacted via discrimination and an oppressive social structure. Furthermore, the social model does not reject the presence of disability, but rather locates it squarely within society (Terzi, 2004: 143; Oliver, 1996).

The argument of the social model is based on Marxist analysis, whereby disability is set within economic and social forces of capitalism that lead to the individualization of people and oppression of those with disabilities. Several leading theorists of the social model have linked the oppression of people with disabilities to the competitive nature of capitalist society. Being disabled occurs due to the social oppression, which is required under the normalization principle of the capitalist system (Barnes, 2000: 444).

The social model has contributed to analysis of the complexity of disability, and it has become the most influential approach after the medical model. It has also influenced political advocacy among disability movements in the United Kingdom, the US and around the world. Thus it has had a major impact on the development of disability studies and the creation of new social policy and inclusive education practices (Terzi, 2000: 141).

The elaboration of the concept of disability among society has been done by Christopher J Rosa (2001). His work is aimed to criticize many scholars in social science that he has claimed to be failed to analyze the American disabilities experiences at behavioral levels regarding to the study of cultures. His work is focused on how people with disability as knowledgeable social related to a community of memory.

In addition, his findings show that Americans from culturally and socially produce the different concepts regarding to disability. Interviewing Americans with different backgrounds and cultures have shown that there are four understandings disability: medical model, rational choice, moral, and community model. His work indeed gives more detailed facts on the conception of disability in America beyond medical model or social model. However, Christopher has not shown how the implications of that perception are. His work is also a study done in a developed country like America where traditional value is not as complicated as in developing countries.

A study by Insa Klasing (2007) elucidates the situation of people with disabilities in the third world, particularly in rural area. In India, although fully 80% of the people having disabilities are living in rural areas, the government and NGOs are mostly concerned with and direct their activity toward urban areas. His work shows how the concept of disability used by Indian government, which is medical model, gearing to the definition disability as “abnormality”. As its consequences, as he describes thoroughly, people with disabilities have been marginalized in rural India. Klasing’s main finding is that social exclusion against people with disabilities in certain aspects of their lives, such as education, can directly affect other aspects of their lives.

Nonetheless, although this book paints a portrait of people with disabilities in rural areas in the third world, and gives the elaboration on the implication of the concept in Indian government, he has not explore the cultural factors which actually has its own concept of disability and how it could give impact to the treatment of people with disability in India. In addition, he also has not explain the other concept offered by disability movement in India and how the concepts are conflicting.

Based on the concept of disability under the social model, according to a thesis written by Jony Yulianto (2008) at the University of Leeds, the disability movement in Indonesia has contributed to new discussions on disability in Indonesia. In his writing, Yulianto defines disability in line with the social model. His work gives clear exploration on the concept of disability produced by Indonesian government and how it is applied in policies; in addition he also explores the concept of disability offered by disability movement in Indonesia, in which disability is defined by social model, and disability as a “social construction”.

### ***Disability, Religion and Traditional Value***

The interesting work related to the concept of disability which is beyond medical model and social model is written by Alyaa Jamal Hamdee (2009). In his work, he claims that in Saudi Arabia, disability has been often approached by medical perspective, using inductive analysis he shows Islamic value really significant in giving impact to the treatment of people with disability. He believes that Islam has been conceptualized to see disability as an object of charity which impacts to the development of disability organization in Saudi Arabia.

His work is really significant to understand the concept of Islam related to disability. Regardless the importance of his work, however, it does not show the conflict between medical approach and Islamic value supporting the development of disability organizations in Saudi Arabia. In addition, Islam is understood depending on contexts and cultures. Islam in Indonesia, as an example, is not similar with Islam in Saudi Arabia. It means the elaboration of disability and Islam in Saudi Arabia does not express disability and Islam in Indonesia.

One interesting work which is more advanced than Alyaa's work is done by Dunya Ahmed Abdullah Ahmed (2007). His thesis focuses on the relation between Islam and disability and women in Bahrain. He argues that Bahrain Islamic teachings are interpreted in such a way that people with disabilities are objects of charity. Because Islam is understood as promoting charity and compassion toward people with disabilities, Dunya Ahmed writes, this understanding is congruent with medical model, and it thus supports the segregation of people with disabilities from others. In addition, popular interpretations of Islam likewise lead to further exacerbated gender segregation. He finds that, for example, visually impaired woman has more disadvantageous experiences than a visually impaired man. However, some groups do try to offer the new concept which is disability as 'social construction'. These groups have been trying to interpret Islamic teachings as voicing support for further social inclusion of people with disabilities, based on equal rights.

Dunya Ahmed's writing is showing many concepts of disability and it's implication toward disabled particularly women. However, the context area he has

explored; disability and Bahrain's Islamic culture are not the same as that is found in Indonesia. Islam in the Middle East is markedly different from Islam in Southeast Asia, and particularly different from Islam in Java, where Hindu and Buddhist cultures significantly influence people's daily lives (Woodward, 1989). Furthermore, elaboration on disability and Islamic cultures out of Middle East such as in Java is truly needed.

Another work concerning the Islamic social world has been written by Majid Turmusani (2003). In this work, Turmusani explores many concepts relating to the perception of people with disabilities in Jordan. Jordanian Islamic teachings which interpreted in such a way that people with disabilities are objects of charity. Medical model following WHO (World Health Organization) defines disability as abnormality applied by government and social model which is offered by NGOs inspired by disability movement in the West (Turmusani, 2003: 47-58)

Although Turmusani explores some cultural aspects that influence people with disabilities, he does not talk in detail about how the production and contestation of concepts of disability affect policies in Jordan. Instead, he focuses on the economic aspects of disabled people in Jordan. He compares the various concepts of disability in Jordan, but he does not focus on how those concepts and its contestation in government policies. Concerning the situation in Jordan, he uses a political perspective to analyze the socio-economic conditions of disabled people, and he explores the rehabilitation and use of participatory frameworks to community development in this society.

The other interesting topic showing the concept of disability is a research done by Patrick Devlieger (1995) on disability in Songye society, Zeire, Africa. He shows that not

all people with disabilities are conceptualized as marginalized people or, in other words, not all of them are disabled due to social oppression. In the Songye belief system, a term equivalent to disability as used in Western society is not found. Within Songye society there are three types of children who are categorized as abnormal: *misinhwa* (ceremonial), *malwa* (bad) and *bilema* (faulty).

In Songye society, children with certain disabilities are categorized as *misinhwa* (ceremonial) children. These children are given special names and regarded as persons who have special powers and have high status in society. Children who are categorized bad children or *malwa* include small people and children with hydrocephalus. Although they are classified as “bad,” these children are also believed to be persons with supernatural powers, who can contact the spirit world and sorcerers. They are seen as visiting the world only for a short time and, afterward, they will return to their own world (Devliager, 1995: 96, in Ingstad, 1995).

In summary, Devliager shows that people with disabilities in Songye society are conceptualized not as abnormal, marginal or deviant figures but instead as people like any others, who have potential and a right to develop their own lives. In addition, disability is not a burden for individuals, but rather a problem of family and community such cultural beliefs integrate them together with other people within society. Devliager’s finding is really stunning; it really differs to what was conceptualized by western scholars such as medical or social model.

Devliager focuses on how culture shapes the concept of disability, such that not all people with disabilities are conceptualized in the same way as in Western society. In



other words, not all social constructions of disability oppress and marginalize people with disabilities. In addition, Devlieger does not explain how the concept of disability in Songye society clashes with other concepts of modernity or development in practice relating to the treatment of people with disabilities.

Stunning concept of disability that is founded by Lenore Manderson and Bhensri Neemirtch (2009) should be mentioned here. They write about how Buddhist moral views concerning the maintenance of individual and social harmony affect popular perceptions of people with disabilities in Thailand. More specifically, the Buddhist ethic encourages that all humans should interact with each other in an emotionally mature and mentally appropriate manner. The cosmological view of Buddhism has a strong influence on people's conceptions of disabilities. Buddhists' views of love and compassion (*metta* and *karuna*) are understood popularly as sympathy and/or pity (*songsarn*), with implications for the social participation of disabled people (Manderson and Neemirtch, 2009). Aside from this, Manderson and Neemirtch's paper does not clearly explain how Buddhist thought has contributed to policy decisions regarding disability in Thailand.

Research done by Ida Nicolassen (1995) on disability in Punan Bah society in Serawak, Malaysia, is close to my proposed research. For Punan Bah society, the mentally and physically impaired are seen as part of the social entity, and they are not excluded. People with disabilities are believed to be the living incarnation of the ancestors, and thus it is a moral obligation for the descendants to respect and take care of them properly, whether they are of limited intelligence, bodily impaired or mentally ill. In this culture, all disabled individuals deserve respect in this world, lest the living receive

ancestral punishment (Nicolasen 1995: 53 in Ingstad, 1995). This view of the disabled is very common in Asia; it also occurs in Borneo, where Nicolasen argues that an individual's ability is not crucial for the formation of social identity. Therefore, the disability of one person is not seen as a burden of that one individual, and he or she will be protected by society (Nicolasen, 1995: 49 in Ingstad, 1995).

Nicolasen's research, however, merely focuses on how culture shapes the concept of disability in ways that are different from western cultures. However, she does not elaborate on how the Punan Bah's concept of disability plays out against the medical model that has been implemented by the Malaysian government. Presumably, the medical model is now, or eventually will, shift popular conceptions as Malaysian culture modernizes, although such concepts may not have changed drastically yet.

Based on this elaboration, we can grasp that sociologists or social scientists have done many works to get the concept of disability and how it's impacts to society. Some of them show the concept generated from the West, and how it's implication in policies toward disabled. Some of them have gone beyond Western concepts with showing concepts of disability related to Islam, traditional-values, and the dynamics within society. Nevertheless, there are hardly elaboration of disability in a society where Islam, traditional-value, and modern concept appear at the same time. Moreover, writing the concepts of disability with its implications in such society will be very significant not only in academic purposes but also for the basic arguments related to disability policies.

## **Disability in Java**

Javanese society in Yogyakarta is a living portrait of traditional mythologies mixed with Islamic cosmology and modernity at the same time. Throughout the city, elements of Hindu and Buddhist belief systems continue to influence people's daily lives, despite the fact that Islam is the dominant religion. Besides, Yogyakarta is also one of the biggest cities in Indonesia with many big universities. This city has also been selected as a pilot project of accessible city in Indonesia.

Unfortunately, there are only few of literatures lucidly talking on disability in Javanese society. In a dissertation written by Makmuri Muklas entitled, *An Evaluation of a Community Based Mental Health Course in Indonesia* (1986), the concept of disability is contested. Makmuri points that, in Yogyakarta, governmental programs for mental health education have not succeeded since the participants are predominantly married women and, with its Western medical orientation, mental health education could to a certain extent be in conflict with what is seen as the traditional role of women in Java (Muklas, 1986). This dissertation explains how the medical model approach, which has been applied by government, is not accepted well within Javanese society, yet the focus of this study is too broad to treat physical disability in any great detail, since the topic is mental health and measurement of the success or failure of government programs. Shortly, the study shows the conflict between medical model of disability and traditional value. However, it is written entirely from the perspective of medical analysis, since it is for a doctoral degree in a department of epidemiology and biostatistics.

One further study that is linked to my topic and that focuses on contested models has written by Inge Komardjaja (2008) about the conflict between the ideal of a ‘barrier-free environment’ and Indonesian cultural paradigms, focusing on the concept of barrier-free environments, which represent attempts to promote accessibility. This is, in fact, not congruent with Indonesian traditional culture, which has feudal and collectivist value systems. Therefore, adopting this concept for developing countries requires critical analysis. In Indonesia, a physical access code has been formulated, but it has not succeed in implementation, since Indonesian collectivist values along with unequal status quos arising from the feudal system do not encourage the independence of people with disabilities.

In her study, Komardjaja provides evidence showing what happened in Bandung and Yogyakarta, where accessible environments are planned to accommodate people with disabilities, but they turned out not to be useful for such purposes. This accessible environment is actually derived from a social model concept that aims to encourage people with disability to live more independently, yet Indonesian culture is predominantly a family-oriented society, and taking care of children, including disabled individuals, is the family’s collective obligation (Komardjaja, 2008: 83).

Nonetheless, Komardjaja does fail to highlight the role of Islam, clearly fundamental in shaping Indonesian cultures, in the conceptualization of disability. Moreover, her focus is merely on the conflict between social model and traditional values. Consequently, she does not discuss the medical approach, despite the fact that it is a dominant model in the treatment of people with disabilities.

If we link these several works on disability, namely, Jony Yulianto's thesis on the role of the social model, Komardjaja's discussion of the conflict between barrier-free environments and traditional values, Muklas's argument concerning the failure of government programs in mental health treatment, Dunya's work on Islam and disability, and Nicolassen's on disability and collectivity in Serawak, Malaysia, we can see that the concept of disability in Asian countries is somewhat complicated, and it requires an explanation of the relation between Western concepts, the medical and social models and their relationship to Asian cultures, as well as the relationship between Islam and disability. Is disability complicated in Java? Like most cultures in Southeast Asia, Javanese society is very communal, and most Javanese are Muslim. Based on this, to fill the gap in the literature discussed above, further research on the conceptualization of disability and its contesting values in Java would be very significant. Therefore, my research in this thesis explores the concepts of disability and the contested concept of disability in Java.

### **Research questions**

This thesis addresses two research questions, which propose to illuminate the issue of disability in Yogyakarta. The first question that will be used for this research is: 1) what are the concepts of disability in Javanese society in Yogyakarta? There are differing conceptions of disability in Javanese society in Yogyakarta, and by exploring these; we will learn the historical background of each belief. In addition, how these beliefs manifest themselves in society shall be scrutinized. Through such elaboration,

this study will trace the changing views on disability and will assess current popular perceptions on the issue.

The next research question is as follows: 2) How are these conceptions contested in Javanese governmental policies, health care, education, and accessibility in public facilities? In other words, it is the goal of this investigation to discover the processes of conflict as they have occurred in Yogyakarta. It shall be ascertained whether these differing views are enacted in specific policies relating to the disabled. There have been many acts of protest regarding discriminatory attitudes toward the disabled, which serve as examples of the conflicting views of the disabled in Indonesian society. Therefore, these changing policies reflect the differing views on disability within society.

By exploring the answer of both two questions, we will the mapping of various conceptions regarding to disability in Javanese society. It will be useful for policy makers and activists of disability movement as basic understandings before making policy related to disability or running programs to make better life for people with disabilities in Java. The elaboration of the answers will provide us what can be 'social capitals' or 'local wisdoms' from Javanese society that can be used to smooth the implementation of inclusive society for all people including people with disabilities.

## **Methods**

For this study, the investigator used an ethnographic approach in order to understand what was happening in Indonesian society. Ethnography is defined by Julian Murchison as:

“A research strategy that allow researchers to explore and examine, the cultures and society that are fundamental part of the human experience. Unlike many other scientific research strategies, the ethnographer as researcher is not a typically detached or uninvolved observer. The ethnographer collects data and gains insight through *firsthand* involvement with the research subject or informant” (Murchison, 2010, 4).

Due to this, the data have been collected through interviews; observation of behavior; listening to conversations; and reviewing newspaper articles, bulletins from disabled rights organizations, their websites, and other relevant materials (Bryman, 2007: 402). The study entailed Three months in the field. However, it is also possible to carry out such studies using micro-ethnography, which focuses on a topic or particular aspect that has already been chosen (Brayman 2007: 403). As mentioned by Julian Murchison, “the power of ethnography as a research strategy stems from its ability to bring the local to specific into sharp focus” (Muchison 2010: 23). Therefore, in this thesis, the conceptualization of disability is the main topic.

I was an activist involved with the disabled rights’ movement in Yogyakarta, and was a member of several unions for people with disabilities. I was also involved in an NGO that advocated and promoted a more inclusive society for people with disabilities. Therefore, I have had a distinct advantage in conducting fieldwork in this area, since I am using an ethnographic method and was involved in the groups’ activities. Nevertheless, this research is not based on my opinion, but rather uses interviews and observations in the field to acquire the necessary analytical depth. The primary data have been collected from people who have been involved in the world of

disability advocacy (i.e., NGOs, government agencies, and people with disabilities). Secondary data has been taken from newspapers, magazines, and other resources.

Since my research relies on ethnographic methodology, the participation and involvement of the community is very significant. Therefore, from May 23 to August 5, 2010, I stayed at Yogyakarta, and have been involved in a disability movement and participated in many of its activities. I also conducted interviews with many stakeholders, including people in disability movements and NGOs concerning disability, government officials, people in disabled organizations, people with disabilities, parents of people with disabilities, general citizens in Yogyakarta, and scholars.

I was also involved in government programs, in which the government and NGOs organized activities for the disabled. These included training activities, disability awareness, introducing assistive technology for people with disabilities, coordinating a seminar, and classes in special schools

In addition, I was also involved with an organization that provides training for people with disabilities to teach them handicrafts such as carpentry and sewing. There are four organizations for the disabled in Yogyakarta that are concerned with providing training in such skills for people with disabilities. I was involved with one of these four groups, and I also performed interviews with people with disabilities in this setting as well as the owner of the institution. Likewise, I visited two rehabilitation centers that treat people with medical disabilities and provide instruction in handicrafts for people with disabilities, even though these people come from other cities. One of these centers was created to serve people with disabilities in Bantul, which experienced an earthquake



in 2006. I conducted several interviews with people there and observed how they treat people with disabilities.

As I am part of the community in Yogyakarta, I have participated in many activities for the disabled, which has enabled me to observe things that I believed were important for my research, and speak with people who advocate for rights for the disabled. I also collected many bulletins published by disabled rights' organizations, obtained data on the disabled from the government, and met with other stakeholders. Initially I planned to interview 41 people. However, during the field research, some of them indicated that they did not want to be recorded. During the interviews, I followed a set of guidelines that ensured each interview would keep to the topic of disabled rights.

### **Theoretical Framework**

The data I report on this study will be explained using theoretical concepts from sociology, which is an appropriate theory to explain differing views on disability in Java. The theory underpinning my research explains the relationship between the various agencies and the contesting discourse they provide. In this case, the sociological theory of *habitus* and *field* introduced by Bourdieu is applicable. Disability in Yogyakarta is a *field* of conflict in terms of meaning. In field theory, agencies struggle and position themselves in relationships with each other in order to define themselves. A *field* is an area of conflict for many *agencies (habitus)* which, based on their history and struggles, compete with each other to determine their identity (Bourdieu, 1991: 231).

Bourdieu argues that conflicts arise within every “field” and aspect of life. Every *habitus* has its own perceptions and, due to durability and similarities absorbed by

people throughout society, classes or groups of people can have their *habitus*, or *habitus* class, or ‘*habitus* group’ Disability in Yogyakarta is an area of conflicting perceptions that call for clearer definition, and views of disability depend on their *habitus*.

*Habitus* is produced by what Bourdieu calls structuring structures, which individuals embody in their daily lives (Bourdieu 1977: 72). *Habitus* is acquired and adhered to by people through experience and socialization in daily life, and subsequent experience is a process of adjustment between objective reality and subjectivity. The objective conditions produce the *habitus*, while the *habitus* itself is reciprocally adjusted to objective conditions. Bourdieu mentions that *habitus* is thus “produced by the process of the dialectic between the internalization of externality and the externalization of internality” (Bourdieu, 1977: 83, 72). In more detail, Bourdieu defined *habitus* as:

“[a] system of durable, transposable disposition structured structures predispose to function as structuring structure, that is, as principle of the generation and structuring of practices and representations which can be objectively “regulated” and “regular” without in any way being the product of any rules, objectively adapted to their goal without presupposing a conscious aiming at ends ...” (Bourdieu, 1977: 72).

*Habitus* is, therefore, a shared body of durable dispositions, classificatory categories and generative schemes as a product of history. Bourdieu argues that *habitus*, a product of history, produces both individual and collective practices in accordance with the schemes generated by history (Bourdieu, 1990, 54) This recognizes the active presence of past experiences, which, deposited in each organism in the schemata of thought and action, tend to ensure conformity and constancy of actions across practices over time, even more assuredly than do explicit norms and rules. Bourdieu makes it clear

that *habitus* is a set of durable, unconscious schemata, which form the foundation of an individual's matrix of perception, appreciation and actions (Bourdieu, 1977: 83).

Bourdieu suggests that social reproductions of reality are not carried out in a vacuum. Instead, cognitive structures are reproduced and structured, since they have social origins that establish the *habitus*. Based on this view, the person or agent is provided with a *habitus* which is shaped in his or her formative years by the environment, such as family culture, which bears similarity and affinity to a larger referential class, or group *habitus*. The group habitus, or class *habitus*, is shaped by collective phenomena that reflect the group members' durable adaptations, conformity and adjustments (Bourdieu 1994: 132). In this regard, Bourdieu adds that,

“In order to define relation, *habitus* and the organic individuality which can never entirely be removed from sociological discourse, inasmuch as, being given immediately to immediate perception (*intuitus personae*) it's also socially designated and recognized (name, legal identity etc.) and it's defined by social trajectory strictly speaking irreducible to any other, the *habitus* could be considered as a subjective but not individual system of internalized structures, schemes of perception, conception and action common to all members of the same group or class and constituting the pre-condition for all-objectification and perception.” (Bourdieu, 77: 86)

There are different social reproductions of cultures between groups, which result in different types of preferences, actions and matrices of perception. People in rural areas may have different musical preferences than people who live in the big city. Those who are highly involved in Muslim cultures are likely to have different perceptions when seeing disability than do people who are highly involved in NGOs concerning disability rights. This distinction derives from the group *habitus*, which is embodied in each person.

The fundamental concept in Bourdieu's theory is capital. Unlike the classic Marxist argument, which defines capital as only a material thing, Bourdieu expands this definition to include: (1) economic capital, including economic resources such as money, homes, etc.; (2) social capital, which could be present in social relationships such as networks and friendships; (3) cultural capital, including education and legitimate knowledge; and (4) symbolic capital, which could be honor and prestige. Such forms of capital are related each other and affect the position of *habitus* (Bourdieu, 1994: 88). They are always determined by *habitus*, which is a product of the internalization of externality and externalization of internality. For example, people from a high socioeconomic class reproduce their cultures, in which capital are fundamental element involved in the process of cultural reproductions. In addition, capital embodied in agency can significantly shape the schemata of actions, matrix perceptions and actions.

A complementary idea from Bourdieu's theory, which is used in this research, is the concept of *field*, namely, a space where different aspects struggle for power and where these aspects meet each other. Fields are social spaces in which agents or structures operate. In the structure of the distribution of capital, whose possession commands access to specific profits that are at stake in the field as well as by their objective relation to the other position. Bourdieu defined *field* as:

“a network, or a configuration of objective relations between position objectively defined, in their existence and in the determination they impose on their occupant agent or institution, by they present and potential situation...in the structure of the distribution of power (or capital) whose possession commands access to the specific profits that are at stake in the field as well as by their objective relation by the other positions (domination, subordination, homology etc.” (Bourdieu & Wacquant, 1992: 97)

Richard Jenkins confirms that, “a field is a structure system of social position, occupied either by individual or institution—the nature of which defines the situation for their occupants; field is structure internally in the term of power relation” (Jenkins 1992: 85).

It is a setting in which in persons or agents and their social position are situated. The position of each agent in the field is a result of relationships among the specific rules of the field. Various social and institutional arenas exist in which people express and reproduce their dispositions, and in which they compete for the distribution of different kinds of capital on the basis of their *habitus*. Those could include fields of art, beauty, religion, education, economics, and concepts of disability.

In other words, a field is an arena of circulation, contestation, and production, as well as a competitive position that holds agency or actors to monopolize it with different kinds of capital in defining and conceptualizing the object such as appreciation, actions and perception. Due to the use of capital as a main factor in this process, all actors participate in processes of production and circulation within the field. Furthermore, the field is often a place of struggle, and the dominant discourse in the field has been internalized and structured throughout society. In this context, in a contested field, due to the significant role of capital, dominant discourses must be distinguished from counter-discourses.

The dominant discourse, which Bourdieu calls a *doxa*, is “the world of tradition experienced as “natural world” and is typically taken for granted. The dominant operates according to “the instrument of knowledge of the social world on this case (objectively) political instrument which contribute to the reproduction of the social world by producing

immediate adherence to the world seen as self-evident and undisputed of which they are the product of which they produce the structure in a transformed form” (Bourdieu, 1977: 164). Thus, the *doxa* is truly embodied and becomes “undisputed truth,” such that it is adhered to in every individual’s daily life, or, as Bourdieu sais, “*it goes without saying because it comes without saying*” (Bourdieu 1977: 167).

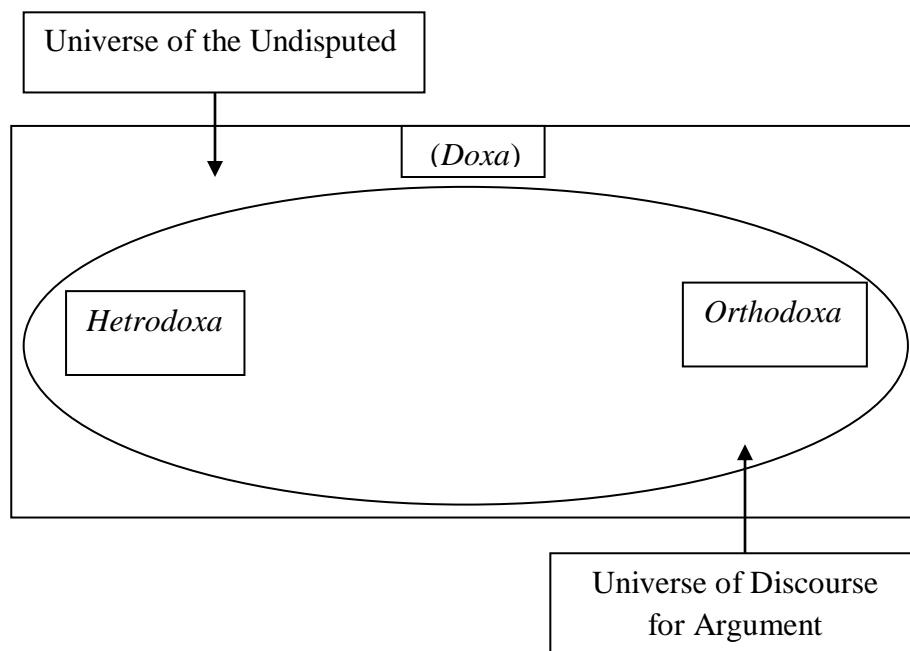
According to Bourdieu, there are, as well, discourses that support the *doxa*, and the dominant group imposes what he calls the *orthodoxa*, whereby a group supports its position of a given *doxa*. On this, Bourdieu says that, “orthodoxy, a straight or rather, *strengthened*, opinion which aims without ever entirely succeeding, at restoring the primal state of innocent of *doxa*, exist only in the objective relationship which opposes it to heterodoxy” (Bourdieu, 1977: 1969). *Heterodoxa*, meanwhile, is the existence of a group that works to oppose and erode “the universe of what which is taken for granted (Bourdieu, 1977: 170). Both *ortodoxa* and *hetrodoxa* contest with each other in a space that Bourdieu calls “the universe of discourse,” and *doxa* encompasses all discourse, since *doxa* is already taken for granted absorbed unconsciously.

Disability in Yogyakarta is, in this view, a field to be contested, a structured system of social positions that are occupied either by individuals, groups or institutions, and which is structured internally in terms of power relations. Disability is therefore present in an arena of struggle to define its meaning. Capital is a fundamental tool for every agent (*habitus*) within this arena.

Individual and collective actors contribute to the contestation of meaning vis-à-vis disability, with each actor reproduces her or his own meaning of disability, internalized

this meaning, and then externalizing it. Every actor has individual history and experiences, which are influential in shaping her or his perceptions of disability. Each actor also has different forms of capital and different ways to produce and absorb the meaning of disability. In sum, each actor has her or his own *habitus*, which subsequently determines the appreciation, actions and matrix of perceptions concerning disability.

**Figure 1: The Map of Contesting Opinion**



For example, an NGO concerned with disability issues would reproduce that disability as a social construction. Topics such as accessibility and the creation of an inclusive society must be a daily conversation among the NGO's members. Due to their education, they are quite likely to have been enlightened by the idea of human rights, critical theories, and by other Western conceptions that influence their perceptions of

disability. The members also learn, update, and share news regarding disability issues. The members of the NGO likewise make connections to other institutions, campuses, and funding donators that support their programs. Having made these circles, they secure funding and knowledge concerning disabilities, and they engage in activities related to disability programs. Clearly, people in such an NGO have their own *habitus*, which would be a basis for their conception of disability.

Like such people in an NGO concerned with disability issues, other groups also have their own *habitus*. People in government have their conception of disability, as well as their own circles, activities related to disability, and so forth. People who are highly involved in Islam also engage in separate activities related to disability. Based on their religious beliefs, they participate in certain programs related to disability. Another concept of disability is the traditional Javanese concept, which is absorbed culturally across Javanese society, structured and installed within society, and supported by ceremonial rituals and other activities that perpetuate the Javanese concept of disabilities.

In this sense, disability is a field, as Bourdieu states, a space of struggle in which every agent's strategy is concerned with the maintenance of improvement. Disability is an object to be defined and a space of contestation among such agents. Disability in Yogyakarta, then, is an arena where many groups of people are attempting to defeat one another. Forms of capital are utilized in this arena and they fundamentally determine the dominant position concerning the contested idea of disability.

The contestation of the concept of disability can likewise be seen in activities, government programs, or people's attitudes within society. This study examines the



contested idea of disability within disability programs enacted by social movements and government policies, which serve as evidence for such contestation. Based on Bourdieu's theory, we will consider this process of contestation and determine what the dominant or marginalized concepts are, and how these concepts contest one another.

## CHAPTER II

### YOGYAKARTA AND DISABILITY

#### **Defining Disability**

Paul Abberley, one of the foremost scholars in the field of disability studies, states that, “The first thing you need to do when talking about disability today is to clarify your terms, and this immediately gets you into the realm of theory” (Abberley, 1999: 1).

Determining first what, precisely, disability is and what can be categorized as such, as well as how “people with disabilities” should be referred to, are fundamental starting points before going further on specific related topics.

Moreover, the definition of disability has been debated, with many scholars and activists contributing their schools of thought and basic philosophies to define the term. This debate and discussion has, of course, affected policies on disability and treatment of people with disability in daily life. In addition, as stated by Edward (2005), the main purpose of forming this definition is to draw a clear demarcation “between disabled people on the one hand and, by implication, non-disabled people on the other.” When one come across references to a deaf person, blind person, intellectually disabled person, or physically disabled person, can we take this as evidence that there is an identifiable category of who people with disabilities are? (Edward 2005: 5).

A second reason for the importance of defining disability is the cultural differences inherent when defining the term. Some cultures regarded deaf people as not disabled, while on the other hand, others believed that people with intellectual disabilities are not. This is the case in some of Western countries where such people are regarded as

disabled, while in Asian countries they are not. To restrict the subject of this study and limit the definition of who should be considered to have a disability, I have used the definition of the American with Disabilities Act and will also provide the WHO's definition (World Health Organization) since they are main sources for defining this term around the world. The legal definition of disability, according to the WHO, is in the following paragraph. In this context, the WHO distinguishes between *Impairment*, *Disability* and *Handicap*. They are each strictly defined and related to one another:

**Impairment:** “any loss or abnormality of psychological or anatomical structure or function, e.g., paraplegia”.

**Disability:** “Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being, e.g., inability to walk”.

**Handicap:** “Disadvantage for a given individual, resulting from impairment or disability that limits or prevents the fulfillment of a role that is normal depending on age, sex, and social and cultural factors for that individual, e.g., lack of wheelchair access to public building or transport because no ramps are provided”.

Different definitions and standards are concluded in the International Functioning of Disability and Health, also known as the International Classification and Functioning, or ICF (2007), which has been ratified by 192 countries. Since it is more current, the ICF is a legal definition of disability from the WHO, which has also become a key source for umbrella legal definitions in many countries. According to the ICF<sup>1</sup>, based on functioning in multiple life areas, *disability* is defined to include seeing, walking, taking a

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<sup>1</sup>It has been used by many countries and become a standard of definition over the world. The official definition of disability from ICF is available at:  
[www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8whodis1.doc](http://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8whodis1.doc). Retrieved 22, June 2011

bath, working, going to school, accessing social services and many such domains. Moreover, disability based on a result of an interaction between a person (with a health condition) and those persons environmental factors or contextual is

“...disability is not seen as an individual's intrinsic feature but a result of interaction in an environment. The interaction of the same person with the health condition may yield different functioning level in different environments”

The IFC also defines disability based on a spectrum, according to three standards: (1) impairments in body functions and structures, (2) limitations in activity, and (3) restriction in participation.

Many countries have adapted this definition for their legislation, though some have added further stipulations. For example, American with Disabilities Act adheres to a stricter and more detailed definition, stating that disability includes: “(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual, (b) a record of such impairment, or (c) being regarded as having such an impairment.” The ADA also describes disability as a condition that may have many criteria, as espoused by United Cerebral Palsy (UCP), an international NGO concerned with disability issues (2011). The following points are will be used to limit the classification of people with disabilities in this study<sup>2</sup>.

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<sup>2</sup> The legal definition from ADA available at: [http://www.ucp.org/ucp\\_channel.doc.cfm/1/13/12632/12632-12632/6184](http://www.ucp.org/ucp_channel.doc.cfm/1/13/12632/12632-12632/6184) Retrieved 23 June 2011

- Mobility Impairment:

“Refers to a person with an inability to use one or more of her/his limb or who lacks the strength to move, walk, grasp or lift objects, including people who use crutches, wheelchairs, and other aids to mobility”.

- Cognitive Impairment:

“Refers to limitations on a person’s ability to understand, learn and reason. People who are categorized for this point are people with mental retardation and learning disabilities”.

- Hearing Impairment:

“Refers to people who have mild hearing loss to total deafness. Those are who hard of hearing often use their residual hearing or may read their partner’s lips when communicating face-to-face. Deaf people using sign language, lip-read, or rely on an interpreter to communicate”

- Visual Impairment:

“Refers to a person’s ability to see, including five points: (1) inability to see images noticeably and obviously, (2) weakness or loss of the visual field, (3) inability to perceive small changes clearl, (4) sensitivity to light, and (5) color blindness”.

- Speech Impairment:

“ranges from problems with verbalization or voice power to complete voicelessness. People with speech impairments may have problems in articulation, projection, or fluency. Some people with speech impairments may use interpreters to communicate or assistive technologies”.

Based on these definitions, this study further explores contested concepts of disability in Yogyakarta.

Many debates on disability, such as those developed in disability studies, rely on the social model by stating that disability is a social construction, reproduced by society, and one is social construction, reproduced by society, and one is only disabled in so far as

one is oppressed by society, or by current scholars who believed that disability has strong relation with social and cultural context will not be discussed seriously at this chapter. The definition of the WHO, the IFC and the ADA described here are merely proposed to make clear who are people with disabilities according to this thesis.

## **A Glance at Yogyakarta**

### ***The Socio-cultural Context of Yogyakarta***

Yogyakarta, or Daerah Istimewa Yogyakarta (Special District of Yogyakarta), is one of Indonesia's 33 provinces. It is bordered by the Indian Ocean to the South, and on other sides by the Central Java Province, including Klaten Regency to the Northeast, Wonogiri Regency to the Southeast, Purworejo Regency to the West and Magelang Regency to the Northwest (Pemerintah Gubernur DIY, 2008: 3).

Founded in 1755, Yogyakarta became the capital of the Mataram Kingdom during the Dutch colonial era. Yogyakarta was the center of several rebellions against the Dutch colonialism in Indonesia, led by *Pangeran* (Prince) Diponegoro and Jenderal Sudirman. Likewise, Diponegoro, a prince of Mataram, proclaimed and waged holy war against the Dutch colonial regime from 1825 into 1830. Diponegoro was a hero to the Javanese people, as he inspired many rebellions that precipitated changes in the Dutch economic policies during the colonial era. In addition, Jenderal Sudirman was an inspiring leader in the Indonesian struggle against the colonial to gain independence (Smithies, 1986: 3-9).

For modern Indonesia, Yogyakarta is the only province to be governed as a traditional kingdom; there are two noble houses that share ruler-ship over the

governmental system in Yogyakarta, with Sri Paku Alaman as vice governor, and Sultan Hamengku Buwono as governor. When Indonesia gained its independence in 1945, Sri Sultan Hamengkubuwono IX or *kasultanan* (kingdom) and Sri Paku Alam VIII or *Kadipaten* (sub-kingdom) proclaimed that they would support the Republic of Indonesia and become part of the Indonesian nation (Smithies, 1986: 9-10).

Yogyakarta, geographically the smallest province in Indonesia after DKI Jakarta, lies between 7°33'-8°12'E and 110°00'-110°50'S, with an area of 3,185.80 km<sup>2</sup>, accounting for only 0.17 percent of Indonesia's total land area (about 1.86 million km<sup>2</sup>). It includes five regencies, namely, Kulonprogo Regency with an area of 586.27 km<sup>2</sup> (18.40% of the total land area of Yogyakarta), Bantul Regency with 506.85 km<sup>2</sup> (15.91%), Sleman Regency with 574.82 km<sup>2</sup> (18.04%), Gunungkidul Regency with 1,485.36 km<sup>2</sup> (46.63%) and Yogyakarta City with 32.50 km<sup>2</sup> (1.02%) (Pemerintah Gubernur DIY, 2008: 3).

Based on official figures published by the government of Yogyakarta, as of 2007, the population of Yogyakarta was 3,434,534, of which 50.16% were men and 49.84% were women. As is the case for other regions across Indonesia, infrastructural development is uneven, with 60.57% living in urban areas and 39.31% in rural areas. Some of the regencies grew more quickly than others. Sleman, Bantul and Yogyakarta City are the three biggest regencies by population size, with annual growth of 1.46%, 1.34% and 1.32% respectively, each of which is higher than average for the province (Pemerintah Gubernur DIY: 2008: 61).

Yogyakarta is a student city, where many students from other provinces around Indonesia came to pursue their studies. There are many universities including the oldest and the best university in Indonesia, Gadjah Mada University. It is one of the most visited cities in Indonesia, after Bali and Jakarta, since it contains many good educational institutions and tourist destinations. This contributes to high population density in Yogyakarta special district of 1,079 persons per km<sup>2</sup> as of 2007. Yogyakarta city has the highest density with 13,881 persons per km<sup>2</sup>, concentrated within only 1% of the province's total area. By contrast, the density of Gunung Kidul Regency is 461 persons per km<sup>2</sup> in an area that accounts for fully 46.63% of Yogyakarta (Pemerintah Gubernur DIY: 2008: 71).

The most dominant occupation in Yogyakarta is agriculture, though this is not sufficient for the province's welfare and prosperity. 32.09% of the population works in jobs relating to agriculture; 21.91% in wholesale, retail trade and grocery sales; 15.13% in providing services; 14.34% in manufacturing; 3.11% in transportation, storage, and communication; and the remaining 14.14% in other fields such as mining, finance and so forth. Based on this data, it is clear that Yogyakarta is both an agricultural zone and a metropolitan city. The official welfare records in 2007 stated that, in Yogyakarta, 21.12% of the citizenry are categorized as pre-prosperous and 22.7% as Prosperous I 23.69.69% as Prosperous II, 26.83 % as Prosperous III and 5.66% in Prosperous Plus. Other data shows that 18.99% of the population lives under the poverty line (Pemerintah Gubernur DIY, 2008: 71).



The economic condition of Yogyakarta can also be seen from employment data; in 2007, there were 139,271 people seeking employment, a decrease of 11.05% compared to 2006. Of these, 56.45% were male and 43.55% female; 43.04% percent graduated from high school, 14.83% with Diploma I-III, 36.64% with a Diploma IV-Degree, and 4.07% from junior high school, with the remaining 0.62% being elementary school graduates. Unemployment stood at 14.35%.

The highest percentage of Yogyakarta's population by age group are middle-aged and elderly, with 10.71% of the population being 25-29 years old, 36.35% being 24 years old or younger, 50.84% being 25-59 years old, and 12.81% being 60 years and older. The relatively high proportion of elderly people shows that Yogyakarta has a high life expectancy. In Yogyakarta, civil servants are classified by rank as first rank (1.05% of the total), second rank (19.70%), third rank (51.99%) and fourth rank (27.26%) (Pemerintah Gubernur DIY: 2008: 63).

### ***The Culture of Yogyakarta***

Yogyakarta is a province in which people have strong traditional cultural values, beliefs and religion. Islam is the dominant religion, accounting for 91.08% of the population of just over 3.5 million (Pemerintahan Gubernur DIY, 2008). The other religions are Catholicism and other Christian demonimations (5.52%), Hinduism (0.18%), and Buddhism (0.17%). Javanese culture and Islam are highly integrated, and in some cases, Javanese people took their cultural traditions and religions as part of one worldview.

Javanese society values togetherness and communality. Unlike in Western society, problems belonging to a person are seen as being those of the group, village or community, as voiced in the traditional saying, “*mangan ora mangan seng penting kumpul*” (“It is not important whether we can eat or not, but the most important thing is togetherness”). This is a well-known philosophy that has become a legacy taken for granted in daily Javanese life. Due to this, if one member of society deviates from the rules of the community, he or she will become ashamed (*aib*), a situation which should be avoided, and can lead one to even become *ora jawani*, which means “unlike Javanese.”

A hierarchical system is strongly apparent in Javanese families and society in general. People who have been regarded as having high positions, such as village leaders (*pak lurah*), upper-class people (*priyayi*), and the elderly should be respected, even in most cases being beyond criticism. *Ewuh* is a feeling people have when it is difficult to say something critical but true to someone, and it is a type of courtesy embedded in Javanese daily life when dealing with people who have a higher position to avoid criticism, even if they are wrong. As a consequence, direct criticism of people who have higher status is rare in Javanese culture.

Javanese society also has systems of respect (*ngajeni*) for older people, such as grandparents, who are spoken to in a high-respect register of speech (*keromo inggil*). Generally for seniors or for people who one does not know well, one should speak with the middle-respect register of speech (*krama madya*). For people one knows well one would speak in the familiar register (*ngoko*); for example younger siblings and children

speak using *ngoko* to show friendship or as a sign of closer relationship (Geertz, 1961: 18-22).

Parents are obligated to take care of and nurture their children, teaching them to become human (*dadi wong*), which means they should know the rules of society, absorb Javanese values and have respect for others. In this case, as Geertz suggests, “unlike some usages in the West, respect here does not necessarily refer to an attitude toward a person superior in power.” Instead, for Javanese, *adji* or “respect” consists of three components: *wedi* (fear), *isin* (shame), and *sungkan* (reluctant) (Geertz, 1961: 110-116).

Newborns are seen in Javanese culture as not merely having a physical body but also possessing their own cosmology and beliefs as they are still close to nature. Parents should help their children to become fully human, including instilling awareness of Javanese rules and values. The parents also should teach their children about life based on societal norms as Javanese, and such consciousness is very fundamental for Javanese people, as expressed in the daily term *durung jowo*, which means “not yet Javanese” and typically refers to a person who is not able to control their emotions and is not yet aware of the Javanese rules of life (Mulder, 1989: 25).

Unlike in Western society, where individuals are predominantly members of nuclear families, most people in Javanese society think of themselves first and foremost as members of extended families. Relationships with relatives are close, and protecting the relationships between families is a locus of honor. This system of kinship is called *kerabat* (familiarity), whereby members of the extended family protect and respect each

other (Geertz, 1961). During the days following Ramadan, a ceremony called *syawalan* occurs in which families reunite as a display of togetherness.

Aside from teaching lessons on Javanese values, parents are also responsible for their children's growth. The parents take this obligation seriously, since they are judged in society by the performance of their children, and a child is rarely asked its name if he or she gets in trouble or has an accident. Instead, the child will be asked, "*anake sopo kowe?*" (Whose child are you?). Likewise, if children perform well according to Javanese values, they will be asked this same question. Thus, parents are the responsible for children in every aspect of life (Mulder, 1989: 27). Metaphysically, Javanese people strongly believe that life is a unity of phenomena in which everything has a place, standing in complementary, coordinated relationships with each other and part of one God's grand designs. This design is seen as constituting a regulated order and world balance (Mulder, 1989: 5).

Due to this, people's actions in the world are also seen as designed by God. Therefore, people should perceive their lot in life and their accomplishments as being for God's purposes. Javanese culture is so infused with Islamic values that being sincere in purpose (*ihlas*) has been absorbed by the Javanese virtue of *sepininging pamrih*, which means not to be guided by ego and to be motivated by the interests of others before one's own personal interests (Mulder, 1989: 4).

Javanese people are also highly conscious of the existence of the group, and its relationship to their individual existence; in short, they believe that, in life, one is not alone. In this connection, Niels Mulder has said that, "people continually [move] into and

out of one another's space and it can only be wise if such contact remain without friction and pleasant by politely acknowledging the presence of other (Mulder, 1989, p.36). This can be seen from common courtesies such as stooping when walking past or giving a greeting with a slight bow of head. Another sign of respect for others can be seen when people enter and sit, in cases where one might rub shoulders with one another, that one is expected to greet and eventually ask for "permission" to go on by putting down their hand and shoulder and saying "*nyuwun sewu*" (please excuse me), whereupon the newly arrived person will invite the host eat with "*moggo*" (please) (Mulder, 1989: 36-7).

These types of exchanges of politeness are obligatory rituals that precede a conversation between guests and their host. The main point of this, as explained by Mulder, is the mutual acknowledgement and respect of each other's existences. Although the people may only vaguely know each other, and may not actually be close, since they are living in the same place and or in the same neighborhood, such a greeting is required as a matter of common respect (Mulder, 1989: 37).

Thus, the Javanese worldview encourages people in their unity and communality both in their imagination of life and their daily practices. Their neighborhood, or *kampong*, is a space for maintaining and perpetuating communality between members. In the *kampong* people are apply their Javanese cultural practives, and people would monitor and rate each other based on such Javanese norms. People who feel at home in a given *kampung*, or community, will participate in ritual activities and celebrations that expressing their togetherness. In this connection, Mulder describes that:

"People who really involve themselves in its life, frequently sitting on all kinds of committees that have the task to organize celebrations and

other neighborhood activities while serving as sources of information and expertise for almost everything that connects *kampong* life with the great world outside. Moreover, they are faithful in making the round of expected visits when a birth has taken place, a marriage is celebrated or when a birth has taken place, a marriage is celebrated or when somebody in their neighborhood dies, honoring such occasions with their presence (*jagongan*) while contributing their share of money and physical assistance (*rewangan*).” (Mulder, 1989, p. 39).

The idea of communal life is to experience the harmonious community, or *rukun*, which generally means maintaining harmonious respect for each other despite differences in opinions or religions. Nonetheless, it is not a matter of course, however, that people will show such respect; instead, it is the result of people’s active willingness to adjust and respect each other in order to maintain a stable condition in their relationships. This willingness is grounded in the principles of recognition and belief that one is neither alone nor self-sufficient, and that one needs others to succeed in life. As a consequence, one needs to be mindful of the expectations inherent in being a member of society. People should treat each other with reciprocal tolerance (Mulder, 1989: 40).

The maintenance of such communal, ordered relationships has been expressed in practices that value conformity and harmony with local standards and in sharing various tasks and obligations such as preparation for and participation in the communal *slametan*<sup>3</sup> and other celebrations or ritual especially around Independence Day and *Suro*, the month of the Javanese lunar new year (Mulder, 1989: 41). On this topic, Mulder writes:

In Yogyakarta people are generally quite conscious of the pressure that communal life places on their existence. Yet they conform, not because of a desire for *rukun* per se, but because good relationships are conducive to a peaceful existence. Highly aware of the existence of

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<sup>3</sup> *Slametan* literally means “having safety,” but it has also become the name of a ritual where many people gather to pray for specific hopes and purposes while sharing in a feast.

other people, the cultivation of good and smooth interpersonal relationship serves the purposes of self-maintenance in a well-defined order (Mulder, 1989, p.43).

### **People with Disabilities in Yogyakarta**

Yogyakarta is an important city for people with disabilities. It's one of the strongest provinces in Indonesia in terms of disability awareness. The city was also established pilot projects to make itself an accessible city for people with disabilities, aside from its position as an area for scholars to come and continue their studies.

Based on the Department of Social Welfare, an official institution handling disability issues, as of 2005 there were 17,727 people with disabilities in Yogyakarta. This population has increases significantly since, on May 27, 2006, there was a major earthquake that killed more than 5,700 people, destroyed more than 156,000 houses and other structures and caused economic losses estimated at over \$3 billion (Elnashai 2008: 5). This earthquake led to an influx into the city of 6,173 newly disabled people.

Generally, most of those with disabilities do not have equal access on a daily basis. Most public services, schools, transportation markets, universities, museums and other public buildings are not accessible for such people, nearly all of whom must also deal with very low incomes and levels of education. It is difficult for such people to secure a job, due to their disabilities, and many rules and laws have been implemented by the government that restricts the number and type of jobs available to them, simply on the basis of their disabilities. As a portrait of their condition, according to *Kompas*, a national newspaper, there are now 1,400 children, who do not have any education at all due to their disabilities, (*Kompas*, April, 29, 2009)

Based on the figures of the Department of Social Welfare, people with disabilities in Yogyakarta are in all of its districts. Gunung Kidul, a rural area in Yogyakarta, is the most populous and has 4,778 people with disabilities, while Bantul has 3,728, Kulon Progo 3,301, Sleman 3,921, and Yogyakarta City 1,945 people. The full population of people with disabilities in Yogyakarta before the 2006 earthquake was 17,727 people, of which 6,656 had physical disabilities, 2,468 were blind, and people who had mental disabilities, 2,786 were classified as psychotic, 2,015 were deaf people, and 809 people were classified as having multiple disabilities. These statistics are summarized in the following figure.

**Table 1: Classification of Disability by Type before the 2006 Earthquake**

	Region	Physical	Blind	Mental		Deaf	Multiple	Total
				Retarded	Psychotic			
1	Kulon Progo	1,212	449	539	480	416	205	3,301
2	Bantul	1,230	562	724	741	394	131	3,782
3	Gunung Kidul	2,164	660	558	688	514	194	4,778
4	Sleman	1,420	512	865	473	452	199	3,921
5	Yogya	630	285	307	404	239	80	1,945
	<b>Total</b>	<b>6,656</b>	<b>2,468</b>	<b>2,993</b>	<b>2,786</b>	<b>2,015</b>	<b>809</b>	<b>17,727</b>

Thousands of children with disabilities are included in this data, namely, a total of 5,505 children with disabilities, of which 2,144 have physical disabilities, 720 are blind, 1,077 have mental retardation, 2,786 are classified as psychotic, 2,015 are deaf and 809



have multiple disabilities. They are treated in special schools, which segregates them from other children.

**Table 2: Classification of Children with Disabilities by Type**

	Region	Physical	Blind	Mental		Deaf	Multiple	Total
				Retarded	Psychotic			
1	Kulon Progo	377	125	159	127	121	52	961
2	Bantul	439	185	255	263	152	41	1,335
3	Gunung Kidul	720	215	229	193	166	41	1,654
4	Sleman	500	147	354	146	142	50	1,339
5	Yogya	108	48	80	23	41	6	306
	Total	2,144	720	1,077	752	622	190	5,505

The population of people having disabilities increased after the 2006 earthquake in Yogyakarta, such that there are now 26,173 people with disabilities, including 8,222 with physical disabilities, 3,384 who are blind, 5,138 with mental retardation, 2,120 classified as psychotic, 2,871 with deafness, and 2,590 with multiple disabilities. Bantul and Sleman both cities most adversely affected by the earthquake, and there are now 5,919 people in Bantul with disabilities and 6,057 in Sleman, while the other cities have 4,441 in Kulon Progo, 4,778 in Gunung Kidul and 2,267 in Yogyakarta.

The government classified those with disabilities after the earthquake as being 8,122 with physical disabilities, 3,384 with blindness, 5,138 with retardation, 2,120 with psychosis, 2,871 with deafness, and 2,590 with multiple disabilities.

**Table 3: Classification of People with Disabilities Following the 2006 Earthquake**

	Region	Physical	Blind	Mental		Deaf	Multiple	Total
				Retarded	Psychotic			
1	Kulon Progo	1,141	642	882	395	497	219	4,441
2	Bantul	2,130	621	937	427	434	622	5,919
3	Gunung Kidul	2,611	1,209	1,366	472	1168	863	4,778
4	Sleman	1,524	619	1,436	500	515	682	6,057
5	Yogya	716	293	517	326	257	204	2,267
	Total	8,122	3,384	5,138	2,120	2,871	2,590	26,173

This data shows that there are about 10,000 people who incurred their disabilities due to the earthquake. We should also keep in mind that the population of Yogyakarta has increased about 57% which is from 17,727 people into people and thus these figures most likely do not include temporary residents who have disabilities. This situation should make government think about accessibility and other policies related to make inclusive society for people with disabilities.

After the earthquake, there were 1,382 children with disabilities in Kulon Progo, 846 children in Bantul, 1,194 in Gunung Kidul, 828 in Sleman and 339 in Yogyakarta,

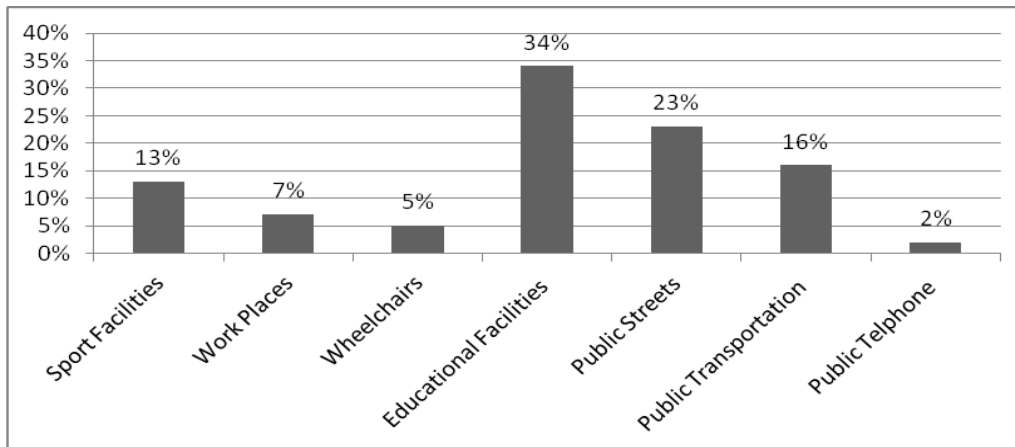
forming a total population of 4,589. Classifying them by type of disability, there are 1,075 children who are physically disabled, 211 who are blind, 1256 who are mentally retarded, 110 psychotic, 564 deaf and 642 having multiple disabilities. We can see from this data that physical disability and retardation are the most common types of disability among children in Yogyakarta.

**Table 4: Classification of Children by Type of Disabilities after 2006 Earthquake**

	Regions	Physical	Blind	Mental		Deaf	Multiple	Total
				Retarded	Psychotic			
1	Kulon Progo	249	33	216	30	141	78	1,382
2	Bantul	207	28	265	22	92	157	846
3	Gunung Kidul	333	81	377	16	184	213	1,194
4	Sleman	184	43	287	18	91	173	828
5	Yogyakarta	102	26	111	24	56	21	339
	Total	1,075	211	1,256	110	564	642	4,589

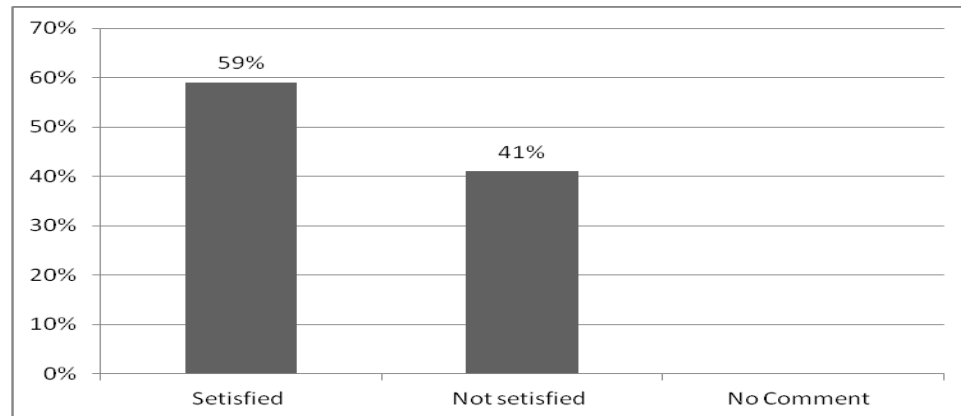
Accessibility is a key problem for people with disabilities. Most public services and places, such as universities, bus stations, shopping centers, hospitals, markets, mosques, and so forth, are not accessible for people with disabilities. This situation implies that people with disabilities are socially oppressed, and many resort to becoming street singers, beggars, and massage professionals, particularly for those who are blind.

**Figure 2: Opinion Survey on Proportion of Public Spaces needing to be More Accessible**



Based on an opinion Survey done by Center of Human Rights Studies of UII (Indonesian Islamic University) what could be done by the government in terms of accessibility, educational facilities were stated by 34% of respondents, 23% said that public streets should be improved, 16% said public transportation, 13% sports facilities, 7% workplaces, 5% stated that wheelchairs should be made more available, as there are people with disabilities who do not have wheelchairs, and 2% said public telephones (Suseno, 2003). This survey is a portrait of how the disabled people's availability of access in Yogyakarta, and of the 4,589 people, 38% of them reported having no education at all. In sum, accessibility is a major problem for people with disabilities in Yogyakarta (*Kompas*, December, 10, 2007) Another survey done in 2003 by Center of Human Rights Studies of UII indicated that 59% of respondents were not satisfied with the accessibility provided by the government, 41% stated that they were satisfied with accessibility (Suseno, 2003)

**Figure 3: Ration of Stratification on Accessibility for People with Disabilities**



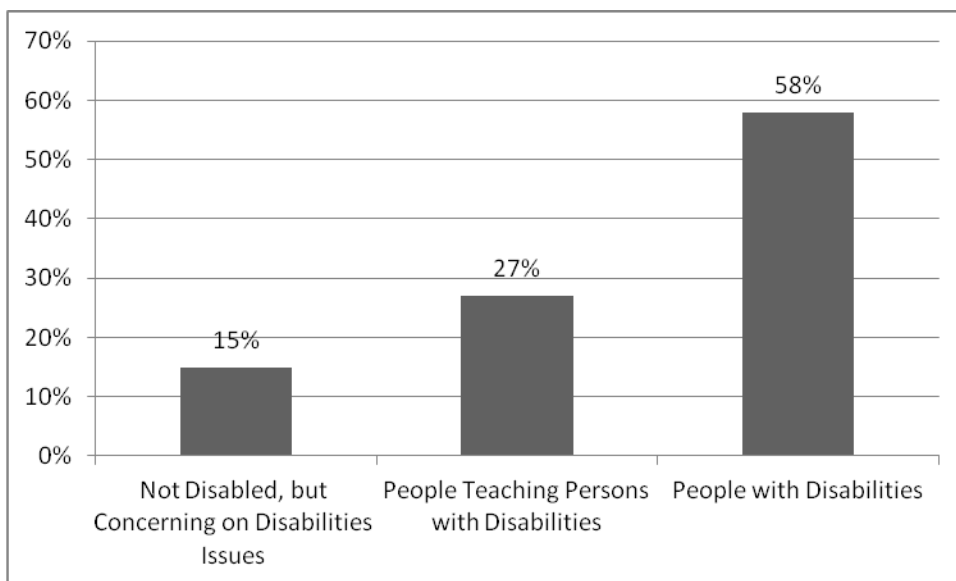
Generally, people with disabilities in Yogyakarta are a minority group in many aspects of life, economics, education, cultures, social, politics, and others aspect of life. They had difficulties in accessing job and educations, besides since the lack of accessibility they are also restricted by admission which is very commonly used commonly in many education institutions, governmental institutions, governmental companies, private companies and so forth. The most common barrier to accessibility is “*sehat jasmani rohani*” (mental and spiritual health), a standard imposed by educational and governmental institutions as a criterion for admission to jobs and to study at universities. This condition subsequently marginalizes such people within society with far-reaching implications.

However, there is a burgeoning movement to voice and demand protection for the rights of people with disabilities, as well as implementation programs for equal rights among people with disabilities, including advocacy, promoting equal rights, economic empowerment, assistance with education, and so forth. Activists in this area may be

disabled themselves or not, but most are involved in some way with disability issues NGOs or academic fields.

Based on a survey in 2003, of the people concerned with disabilities and involved in the struggle to elevate the conditions of disabled people condition, 15% of such activists were not disabled themselves, 27% were teachers for people with disabilities, and 58% had disabilities themselves. In sum, people with disabilities play a strong role in advocating the implementation of their own equal rights (Suseno, 2003)

**Figure 4: Figure 4: Types of People Involved in Disabilities Concern and Activism**



Regardless the conditions of people with disabilities in Yogyakarta, and of the types of people struggling for disability rights, it is clear that Yogyakarta has become the most significant city in Indonesia's disability rights movement. Since 1990's, Yogyakarta has remained at the forefront of those pushing for a new concept of disability. For example, in the 1990's, Malioboro, a famous street in Yogyakarta, became a pilot project for establishing accessible areas for people with disability in Indonesia.

Yogyakarta is the central spot of the disability movement in Indonesia. The disability movement, inspired by the social model that emerged in the United Kingdom and that sees disability as a “social construction,” came to Indonesia for the first time in Yogyakarta. Mansour Fakhri and Setiadi Purwanta, two blind people, introduced the term *difabel* in reference to people with disabilities, meaning “differently abled people.” They believe that the Indonesian term *disabilitas* which means disability, or *penyandang cacat* (people with disability) reproduce an ‘ideology of normalism’ and discriminate against people with disabilities in society. The prefix “dis” means “can not,” so that they advocate replacing the term with “difabel,” as they believed that every person has his or her own abilities (Purwanta 2004 in Suharto and Munandar 2004: 23).

The long struggle of the disability movement to make an inclusive society has produced results. Many new regulations show that still there is a hope for people with disability to get equal access. In Yogyakarta, regulations on disability follow the national regulation, including *UU NO 4 Tahun 1997*, regulating people with disabilities in general such as culture, health, education and so forth. A second piece of legislation is *Peraturan Pemerintah No 43 Th 1998*, a regulation on social welfare for people with disabilities. Presidential instruction no. 82 1999, or *Keppres no.82 tahun 1999*, meanwhile, regulates social welfare programs for disabled people, and Ministerial instruction *Keputusan Menteri Pekerjaan Umum RI No. 468/KPTS/1998 tentang Persyaratan Teknis Aksesibilitas* concerns accessibility for public services.

However, there are also local regulations (*Perda*) including *Peraturan Daerah Nomor 11 Tahun 2002*, a regulation on providing facilities and accessibility for building

and environments within Yogyakarta. Likewise, *Skep Dirlantas Polri Nomor Skep/22/IX/2005 tanggal 22 September 2005* is a police regulation on the transportation of disabled people. One last example is the official police directive *Surat Nomor B/4965/XII/2008/* which allows people with disabilities to apply for driving licenses.



## CHAPTER III

### PRODUCTION OF DISABILITY CONCEPTS IN YOGYAKARTA

Yogyakarta is a living portrait of traditional mythologies mixed with Islamic cosmology. Throughout the city, elements of Hindu and Buddhist belief systems continue to influence people's daily lives, despite the fact that Islam is the dominant religion. For many people in Yogyakarta, Islam is not as strict as is the case in the Middle East. Muslims in Yogyakarta are more flexible in their Islamic ideas, as they also continue to believe strongly in Javanese myths, cultures and rituals, which have roots in Hinduism and Buddhism.

#### **The Javanese Conception of Disability**

People in Java believe that there is a spiritual connection between Merapi, the active volcano, together with the sea and people's lives. In the middle of the town is a monument symbolizing the Sultan's union with God. Kraton, the historical kingdom of Java, was believed by its people to have special connection with *ratu kidul*, a queen of the southern oceans (Woodard, 1989: 16-17). City management and design throughout Yogyakarta are based on these cosmological beliefs concerning harmony and balance of the world and life.

To retrace the Javanese concept of disability, we should turn to its people's myths, norms, cultural ceremonies and cosmological views. Based on these, we can gain a better understanding of the notion of disability for Yogyakartaans, as reflected by and

adhered to in Javanese people's daily lives. As mentioned in chapter two, Javanese society emphasizes communality, expressed in the spirit of *rukun*. Franz Magniz-Suseno argues that *rukun* is the means by which Javanese people maintain peaceful relationships with one another.

“*Rukun* is marked by cooperation, mutual acceptance, calm and unity. *Rukun* is the ideal situation that Javanese wish to see prevail in all relationship, in the family, neighborhood, the village. The entire society should be determined by the spirit of *rukun*” (Magniz-Suseno 1997: p. 43).

Therefore, every person should maintain the spirit of *rukun* in his or her day-to-day life. For example, fathers should take care of their children until the age of *njawani* (becoming Javanese), meaning that time by which they can understand and follow norms and social systems based on Javanese principle. Parents are thus responsible for the ethical performance of their children, and the rest of society judges them according to this responsibility in every aspect of their children's lives. Every person should keep such balance, togetherness, and unity in their daily lives.

This type of belief and spirit of life imply that families protect people with disabilities. Older family members assist younger members, including the disabled, in their activities and do not put people with disabilities separated from their homes. Elders perceived their children's disabilities as part of their responsibility. Even more than this, for people in Java, life is part of the all-pervading unity of existence, and all elements of life and society should stand in complementary and coordinated relationships with one another (Mulder, 1989: 5).

### ***Disability in the Story of Wayang***

Elements of disability as a part of the Javanese worldview can be seen in the stories of *wayang* (puppet). Benedict Anderson (1965: 5) has said that *wayang* is a “compelling religious mythology” that unites the entire Javanese people geographically and spiritually. *Wayang* presents an ideal view of Javanese life and serves as a guiding narration, a reference of real life in the world. Smithies (1986:37) further states that, in Yogyakarta, *wayang kulit* (shadow puppet) is the dominant art form in Java, contributing to the dominant way of thinking, meaning that it shapes people’s views of life rather than being simply an aesthetic distraction; since “the wayang kulit engulfs People’s ways of thought, almost everything seen in the term of wayang” (Smithies, 1986: 37).

The origins of *wayang* stories can be found in the Indian Mahabarata and Ramayana. However, not all of the stories of *wayang* in Java completely replicating those found in the Mahabarata and Ramayana. *Wayang* stories were well established as clearly as the Majapahit Kingdom, a Javanese Kingdom which was based in Java from 1293 to around 1500. In the stories of *wayang*, people with disabilities serves as significant characters, and through these stories we can see expressions of the position of people with disabilities in Javanese cosmology.

One of these stories is regarding Durgandini, also known as the Dewi Lara Amis, the daughter of deity Virata. She is a woman who has a peculiar deformity on her body, with peeling and blemished skin. Due to her disability, she was exiled to the middle of a jungle, where she became a rowler for people who desired to cross the holy mighty Gangga River. One day, there was a hermit, Palarasa, who met Durhandini. She touched

Palarasa's heart, and then Palarasa cured her of her disease and took her as his wife. They had a son who was also disabled and deformed, named Abiasa. He was then taken to the hermitage Saaptarga to learn the ways of witchcraft, sorcery, and other forms of magic which later made him a hero who would help other people. Given his magical powers, he had the expertise to solve complex problems and become respected by people in general.

Another story concerning disability is about the origin the deity *Dewa* (God). After Wicitrawirya passed away, his mother Setyawati sent his wives Dewi Ambika and Ambalika to meet *Begawan* Abiasa at Mount Saptarga to ask for his fertility blessings. Within the meditation room, the guru Abiyasa, with a supremely powerful face and glowing eyes, held a ceremony to beg for Ambika and Ambalika to be fertile. Ambika shut her eyes upon seeing Abiyasa, and thus her baby, named Destarata, was born blind. On the other hand, Ambalika tried not to close her eyes during the ritual, and thus her baby was not blind but did have pale skin and a pale face. Later, her child was given the name Pandu, which means "pale." Destarata, who was blind, and Pandu with his strange face were not ordinary people. Destarata had 100 sons who were called "Kurawa" and became symbols of evil, while Pandu had five sons, called "Pandawa," who symbolized goodness.

Another element of disability in *wayang* could be found in the stories of the Punokawan. In this *wayang*, the Punakawan were people were regarded as a humorous group of people who served and stood beside others. Keeler has said that the Punokawan were:

Of low status, deformed and dependent, the punakawan might seem to be a perfect representative of what Victor Turner calls marginality—anti-heroic, anti-structural, domain of those who criticize and reject the distinction on which society’s power structure is based [Turner, 1966]. But unlike the role of marginal figure in many cultures, the punakawan are neither satirical nor critical. They are non-structural in that they wield no official power, but they are not anti-structural. (Keeler 1987, p. 210)

Regardless on the position of the Punokawan in *wayang*, we can see that disability was a significant thing which appeared with many figures in *wayang* stories and has been regarded not as abnormal but rather special and supernatural.

However, Keeler’s point is debatable, and his analysis of the Punokawan is not true. On the contrary, Punakawan have been a pivotal figures in *wayang* stories and their positions are low position. To the contrary, they are wise people and had a significant role in many scenes, handling situations by bringing back order, since they “can help to change chaos to harmony” (Sumukti, 1990: 21). Then who are Punakawan? They are four disabled persons, described by Benedict Anderson as the “best loved figures in all wayang.” They are named Semar, Petruk, Gareng, and Bagong. Semar is a father figure with a fat and crooked body. Gareng is the eldest son, deformed and a dwarf with sores and a crooked, disjointed arm. Petruk is the third son, with a scrawny body, big belly, misshapen mouth, long nose and a pair of stiff, useless hands. The last is Bangong, and has what Anderson calls the “typical Punakawan deformities,” including a hernia, a bald head, and a bulging fat belly as well as a crooked body shape. Clearly, disability is a salient aspect of the Punokawan body (Anderson 1967: 43-45).

The Punakawan serve in most stories to maintain balance in the world.

Historically, they are actually the offspring of the *Dewa*, or dieties, sent to keep the world

balanced and to serve the Pandawa. They come to the world to help Pandawa solve difficult problems and to teach the world with wisdom. The most significant figure in Punokawan is Semar, the father of all Punakawan, and a humble, funny, and wise figure. In real life, there are many cases where Javanese people dealing with a difficult national situation, such as a crisis, will refer to Semar. People who have special cunning or special disabilities are referred to as Petruk or Gareng. However, Semar is the most important of the Punokawan, and in daily life he is the one that most people refer to as a paragon of wisdom.

On the role of Semar, Sumukti (2005) argues that he is able to offer wisdom and power that other characters lack. For example, in the *wayang*, Semar interacts with the Pandawa who are actually his superiors and also *ratu adil* (just rulers); he helps them to solve problems by teaching the nature of life, wisdom, and the essence of humanity.

“... In wayang kulit, semar is a servant of the Pandawa, but he is highly respected by his master. He is usually consulted by them on decision concerning serious matters...since Semar is a symbol of human mind which provides wisdom, he is exactly where Arjuna is. Semar can be invisible, but presents in Arjuna’s mind in the form of all his past teachings. Semar in different of his analysis is a symbol of the cosmos, he is the symbol of the earth as well, for he is identified with the *gunungan*” (Sumukti 1990, p. 7)

Semar represents the essence of Javanese culture and its emphasis on creating balanced relationships and harmony. Semar is a key element of *gunungan* (mountain), the Javanese cosmology regarding the order of the universe expressed in the outline of the plot (*kelir*) at the beginning and end of *wayang* performances. *Gunungan* is the symbol of daily life and the reflection of universal order in Javanese cosmology.

These explanations lead us to conclude that people with disabilities in Java are significant to the Javanese worldview, as disability is associated with supernatural powers at the core of Javanese culture and cosmological beliefs. As the stories of *wayang* reflect Javanese society, it is no wonder that, in real life, the disabled are in important positions and contribute to the power of the king, thus becoming an integral part of the life of the Javanese kingdom.

The concept of disability as a form of power and magic has existed for a long period in Javanese society, and it has therefore been internalized and externalized as beliefs that are expressed in people's daily lives. The concept of disability as a type of magic absorbed by people structures Javanese subconscious thought, as such perceptions of disability have become part of their *habitus*, concealed under its subjective nature (Bourdieu, 1977: 79). Within this *habitus*, such a concept of disability produces a seemingly objective, commonsense worldview, taken for granted in how it informs practices, appreciation and perceptions. John Pemberton offers a similar explaining in his description of how Javanese society regarded people with disabilities as having magical powers that are not separate from day-to-day life (Pemberton, 1994). Those with disabilities were also regarded as having the gift of prophesy. It was believed that they could pick winning lottery numbers and predict gambling bets. People often consulted with the disabled to acquire luck or to find out the winning lottery number for the next day.

### *Disability in Javanese Life*

In modern Javanese life, however, we do not see definite actors that presume the concept of disability as magic, as it has now become a part of the “myths” of cultural practice. Since people with disabilities were regarded as people having supernatural powers and deserving of high respect, Benedict Anderson (2000) argues that people with disabilities and midgets could be found in Javanese castles. These special persons were regarded as having powers to strengthen the position of the Javanese kingdom and the power of the king. The magic of disability is a form of symbolic capital which is produced to support the concept of Javanese royal power, something that is considered as a shining lantern at the center of the world. People with disabilities are heirlooms that strengthen the power of those in positions of authority, such as the king (Anderson, 2000).

Generally, however, we could find people who believe in disability as a form of magic in the rural area. They believe in the wisdom behind the story of *wayang* and traditional Javanese culture that influence the way they see disability; as magical phenomenon and an important aspect in their lives. These people belong to lower class society and live in rural villages such as Bantul, Sleman, Gunung Kidul, and Kulon Progo. When it comes to education and occupation, most of them do not have access to modern education and they work as farmers in rice fields, vendors in traditional markets, or low level civil servants

The perception of physical and mental disability as magic also spreads out ubiquitously in urban area and to the people living around *kraton* (Yogyakarta royal



palace). A lot of people, especially within the older generation, believe in the power of the disabled. In the young generation however, although the belief has been gradually eroded by modern rationality they got from modern schools, it still exists in people's lives.

Due to their backgrounds, income (material capital), knowledge (cultural capital), ruralism (social capital), and low access to modern education (cultural capital), they steadily re-produce disability as a magical aspect in their lives, as seen in daily-practices. The belief proceeds in their daily lives and adheres to what Bourdieu called "the process of the dialectic between the internalization of externality and the externalization of internality" (Bourdieu, 1977: 83, 72). Those are the background and the history that become the basic of what Bourdieu called 'unconscious schemata', which forms the foundation of an individual's matrix of perception, appreciation and actions (Bourdieu, 1977: 83).

The element of disability as magic can be seen from the daily activities inside the *Keraton* (kingdom) where groups of people with disabilities or *abdi dalem polowijo* always accompany the king. On the role of disability in the daily life of the *keraton*, Hughees-Freeland has said:

The private detail of the future sultan's domestic arrangements was matched by day-today stories about collection of items necessary for the ritual at the accession. The more bizarre the event, the more extensive was coverage, as the the search for seventeen, *abdi dalem polowijo*, and special retainers who are albinos or dwarfs, whose strengthens the power of sultan... (Hughees-Freeland, 1991, p. 133)

Many ritual ceremonies of the Javanese kingdom highlight people with disabilities as playing a significant element and serving as symbols of both power and protection of all people. Therefore, we can say that the concept of disability as a form of magic in such rituals is a type of symbolic capital that belongs to the kingdom.

In various rituals organized by the *kraton* or inspired by the culture of the Javanese kingdom, many also use elements of disability. For example, the ceremony of *mubeng-beteng* (taking a round fortress) is a ritual in which participants march around a fortress, held once a year to welcome the new year. In this ceremony, “being mute” is employed as a symbol of calmness and humbleness, as well as an emblem of the harmony of Javanese community. The participants believe that becoming mute is a quiet way to create harmony for natural life.

It is also practiced in people’s activities which take place in a rural area around Merapi Mountain. This symbol is also used in the response to recent eruptions of the active volcano, Mount Merapi. The keeper of Merapi, who is usually called *juru kunci*, Mbah Marijan, together with the local villagers, walk around Merapi while staying mute in order to restore peace and calmness to the mountain and to persuade Mbah Petruk, a god of Merapi who is also disabled, to not become angry. Then we can see that the elements of disability are apparent in people’s beliefs. Disability is likewise a symbol of the patron deities of each month, another element that is meant to maintain the harmony of the universe.

People in Java believe that Merapi is guarded by a god named Mbah Petruk, who is a son of the Punakawan. Petruk is disabled and he holds a position as the keeper of

Merapi to maintain balance in the world. When crisis and chaos happen in Yogyakarta or nationwide—such as a misuse of the government authority, corruption, the increase of the wealth gap between the rich and the poor, social injustice, and so forth—Mbah Petruk will be angry and he will warn Javanese people. The eruption of Merapi is how Mbah Petruk shows his anger for what people have done in the world.

In everyday life, people with disabilities received special treatments, and would be regarded as having powers to exact supernatural revenge if they are hurt or humiliated. Thus, due to their powers of prediction, for example, people with disabilities are seen as advisors for those who play the lottery. Those perceptions are still alive in modern everyday life, as one can see people at street intersections asking questions of the disabled about *Togel* (a type of lottery), and asking about what lottery number will appear that night or next week. The disabled “advisors” usually answers such questions randomly, but the event itself is in line with my interpretation of their place in Javanese traditional culture.

In addition, the Javanese believe that insulting the disabled may bring adverse impacts on their children or descendants. *Keteplok* is a term that expresses this belief in a sort of karmic retribution to those who insult those with disabilities, as the children or grandchildren of people who so insult the disabled will become *keteplok*, disabled themselves. Regarding this belief, Javanese people would think again before insulting people with disabilities. Moreover, the disabled are seen as people whose prayers are more efficacious and easily answered by God.

Various elements of disability, regarded as symbols of Yogyakarta, can also be found in monuments, murals, shop names, advertisements on busses, and so forth. Pictures of *punakawan* could be found adorning the walls of Javanese houses, as they serve as talismans for success in trade or bestow other benefits. Even places of education also use Punakawan as a symbol, with images of Petruk, Gareng, Bagong and Semar as decorations on the walls. Clearly, the concept of disability as magic structures Javanese society such that related symbols are readily apparent in the everyday life of society is very much embedded within people's worldviews.

Based on the elaboration, it could be concluded the source of the power (kingdom) maintaining Javanese culture, of course, is not only the actor responsible for the process of structuring the perception, but some people believing disability as magic from rural areas, the older generation and people around *keraton* as mentioned above are participating into this process. The perception of disability for Javanese people therefore becomes a type of symbolic capital, maintained by the kingdom to strengthen and keep its power. The balance system and harmony of the universe, in which disability becomes a significant element, is a symbolic power that fertilizes Javanese culture.

If we adapt this to Pierre Bourdieu's theory, the magical power of disability is durably reproduced within the structure of society. It has been absorbed for a long time by individuals who come from lower class and live in rural villages or the old generation with low access to modern education. *Habitus* is, therefore, a shared body of durable dispositions, classificatory categories and generative schemes as a product of history. (Bourdieu, 1990, 54).

The background then becomes a scheme of history which is determinant to the conception of disability. Each of the individuals probably does not have identical history and experience, but they share the homologous ones, and each of the individual system of disposition can be seen as a structure of all the members of the group or class (Bourdieu, 1977: 86). They form a common perspective. Thus, homogenization has produced collective dispositions that are, themselves, “internalisations of the same objective structures” (Bourdieu, 1977: 81).

Moreover, as stated by Bourdieu, *habitus* is always a “durably installed generative principle of regulated improvisations” (Bourdieu, 1977: 78), and there is always a room for improvisation among those in Yogyakarta who believe the magical aspect of disability. Every individual in Yogyakarta is not passive in this process, but the perception of and schemes of thought concerning disability form as part of the *habitus* as well as schemes of thought and expressions that “produce improvisations which are consistent and which thus appear sensible and valid” (Bourdieu, 1977: 79). Since disability in Yogyakarta is a field in which many people have contesting perceptions, the traditional perception of Javanese society on disability as outlined above has been supplanted by modern medical perceptions of disability; disability is an object of medical study has become influential in shaping government policies relating to people with disabilities.

## **Disability and Islam**

Another significant thread that contributes to the concept of disability in Javanese society is faith in Islam. As mentioned above, Islam is a dominant religion in Javanese cultures, as more than 80% of Javanese people are Muslim. The perspective of Islam concerning disability should therefore not be ignored. Moreover, the treatment of the disabled in modern Javanese life has been influenced by Islamic teachings.

Nonetheless, the Muslim community in Indonesia does not have the same worldview as do Muslims in the Middle East. In Indonesia, Islam is mixed with various types of local mystical beliefs and local cultures. In Java, many people declare themselves as Muslim yet do not practice their religious rituals. Such people are called '*abangan*', literally "the red" as they claim they are Muslim but do not practice in religious ritual activities. This group is quite large and influential in society, including in politics. The other group is called "*santri*", which is a group of people who practice and learn Islamic teachings. More currently, this group has been increasing in size in urban areas, where Islamic rituals and symbols are often seen. The next group is called '*priyayi*', a group that represents the official kingdom or government. Generally this group is very close to the *abangan* in terms of religious beliefs, but some of them, particularly after the collapse of the Suharto regime, openly practice Islam (Geertz, 1960).

To unravel how the disability and the Islamic perspective of disability plays out in Java, we should first briefly explore the theological teachings of Islam on disability. This will allow us to have an in depth view of how Islam has influenced Javanese people's

views on disabilities and how such concepts have become influential in Yogyakarta society, both in terms of the general treatment of disabled people as well as in light of government policies on disability.

### ***Disability in Islamic Texts***

Basically, Islamic concepts on disability continue in this normative tradition. In the Islamic perspective, disability is part of God's punishment for mankind's sins and unlawful acts. Besides, it sees people with disabilities as the weak who should be helped and given charity by other people, or in other words it perceived disability as an object of charity.

As Mohammed Ghaly has said, some scholars believed that the Koran verse "Whatever misfortune happens to you is because of the thing your hands have wrought, but for many [of them] He grants forgiveness" (42:30) refers to disability as part of God's forms of punishment (Ghaly, 2010: 43). A negative perspective on disability is likewise found in Islamic views about leprosy, as the Prophet Muhammad himself is said to have taught that Muslims must avoid leprosy as they would wild and ferocious lions. Those who contract the disease should be segregated from others to avoid contagion. (Dols, 1983: 891-916).

In other cases, we can find statements in the Quran portraying disability as, for example, an evil symbol of unlawful action or a sign that a person did not pay attention to what was said by God. In this verse, we also can clearly see a bias in favor of physical normalcy. This is also illustrated in the fifth verse of *Surah Al-hājj* (the pilgrimage), which reads:

O mankind! If you are in doubt about the Resurrection, then verily! We have created you (i.e. Adam) from dust, then from a *Nutfah* (mixed drops of male and female sexual discharge i.e. offspring of Adam), then from a clot (a piece of thick coagulated blood) then from a little lump of flesh, some formed and some unformed (miscarriage), that We may make (it) clear to you (i.e. to show you Our Power and Ability to do what We will). And we cause whom we will to remain in the wombs for an appointed term, then We bring you out as infants, then (give you growth) that you may reach your age of full strength. And among you there is he who dies (young), and among you there is he who is brought back to the miserable old age, so that he knows nothing after having known. And you see the earth barren, but when We send down water (rain) on it, it is stirred (to life), it swells and puts forth every lovely kind (of growth). (Hilali and Khan, 2000, p. 429)

It is common for Islamic scholars to interpret the words “formed” and “unformed” here as meaning disabled and not disabled. If we look into the original Arabic version, here the Quran uses the word *halaqah* which literally means “completely created” and *Ghoiru Muhallaqoh* “incompletely created.” This is in line with Tabāry Al-Baydlawy and al-Qurtuby, the famous Muslim intellectual who interprets the Koran also believe that *muhallaqoh* means “perfect” as in having two hands and two feet without disabilities. Therefore, the *ghaira muhallaqoh* are those who are born with physical disabilities. Al-Maraghi interprets the word *ghoira muhallaqoh* as referring to those who are born with small bodies, or midgets. Tabāry, another well-known interpreter of the Quran, says that the word *muhallaqoh* in this verse refers to “normal people,” and the word *ghoira muhallaqoh* refers to babies who are born with physical deformities or who die in the womb, which sees babies with disabilities as being unfinished or yet human (*Buletin Ikhtilaf*, 124<sup>th</sup> Edition, 2000).



Discrimination against disabled people in Islam can also be found in several verses of the Quran that refer to disabled people negatively, portraying disability as a symbol of unlawfulness or disobedience to what was said by God (Hilali and Khan, 2000):

Not alike are the blind (disbelievers in Islamic Monotheism) and the seeing (believers in Islamic Monotheism). (35:19)

And if it had been Our Will, We would surely have wiped out (blinded) their eyes, so that they would struggle for the Path, how then would they see?

In Java, the stories of the ideal type of people, based in prophetic tradition, states that the ideal type of God's *ummah* (followers) are those who are able to wrestle, to ride horses, to swim, to compete in archery and perform other physical activities. This ideal type of people shows how Islam conforms to normalcy and neglects those with disabilities.

This is how disability is portrayed in Islam a perspective that has also shaped the views of people in Java, and which has been reproduced as a significant element of their *habitus*. Such views are still significant for Javanese people since, despite shifts in society, the 'quranic verses' do not change and are used as reference points for thought.

### ***Disability and Islam in Java***

The perspective of people having disabilities being objects of charity and the view that both people who need help and those who help them will multiply their merits and spiritual wealth is well installed within Muslim society. In this case, the role of Islam

shapes such perceptions. In reality, people in Yogyakarta do many activities relating to people with disabilities, and some of them are based on Islamic teachings.

A story describing the influence of the Islamic perspective on disability is that of Imam Syafi'i, the most popular school of Islamic thought in Indonesia. There has been a widely known story in Java regarding Imam *Syafi'i*, in which it is said that, once upon a time, he walked along a riverbank and came across a pomegranate. The guru took and ate it without knowing who owned the pomegranate. He suddenly remembered that it belonged to his teacher, who became angry because he really needed that pomegranate. Due to his blunder, the teacher punished him by decreeing that he must marry a person who was deaf, blind, and disabled. This story has been narrated in the *pesantren* (Islamic boarding school with dorm), *madrasah* (Islamic boarding schools) and *pengajian* (meeting places for Islamic speeches and debates), and nearly all people in Java, particularly those from *santri*, are familiar with the story.

Muslim perspectives on disability in Java are clearly biased in favor of normalcy. A further example of the influence of Islam in Javanese society supporting normalcy is seen in the upsurge of teaching *tajwêd*—the proper way of pronouncing and reading the Quran—as ideal reading is important during prayer or other worship. This strengthens the spirit of normalcy and discriminates against those who have disabilities that would, for example, prevent them from ever becoming an *imam salat* (prayer leader) or participating in other ritual activities.

Those who are regarded as feeble and weak are considered difficult cases at the core of Islam, since they are a group that requires the giving of *rukhsah*

(dispensation) or *ishtisnā'* (expectation) to compensate for their “abnormalities”

However, such gestures are not ideally or perfectly performed. Clearly, region is set up to adapt to normalcy and strengthen the position of non-disabled people in the social system.

Many Muslims believe that people with disabilities belong in an inferior position to those who are normal, since it is taken for granted that they could not be leaders in religious rituals or become an *imam* (leader) in prayer. In Java, people recognize that if there are normal people to perform such roles. They should not be given to one; as Ghany states, for a disabled person to serve as an *imam* is grounds for a situation of *makrūh* (better to leave).

Another portrayal of Islam that subordinates people with disabilities in Java is the perspective that people with disabilities cannot serve as leaders in general. This perspective is espoused in a book written by Al-mawardi, *Al-ahkām Al-šulṭoniyah wa Auliyaṭuth Addiniyah*, one of the *kutub al-muktabarāh* (verified books) that has become a reference for both Nahdlatul Ulama and Muhamadiyah, the biggest muslim organisations in Indonesia.

Due to the influence of Islamic perspectives in shaping people’s views in Yogyakarta, most Yogyakartans believe that disability is a test of people’s lives and their faith. People who can deal with their problem will be reserved a special place in the afterlife. People who could deal with the test of disability will receive mountains of merits and special rewards from the God. This belief is reproduced, internalized, and

absorbed by muslim people particularly Santri. Most people with disabilities believe that they are undergoing tests from the God to make them better in their life.

In addition, Islam suggests that people should help *mustadhā'afin* (the weak). As people with disabilities are regarded as the weak, they are objects of charity for Muslim philanthropy. Moreover, some Islamic doctrines require and suggest that people should donate some of their wealth for the weak, and it is congruent with Islamic teaching that *zakat* (giving alms), one of the most important pillars of Islam, should be provided to the weak. Muslim scholars have stated that people with disabilities are members of the *mustadz'afin*, even if they are not specifically mentioned in Islamic texts. People with disabilities also become the object of *shadaqoh* (offering alms), a practice that is strongly recommended in Islam, though it is not compulsory (Ghaly, 2010: 159-160).

The perception has been re-produced among the Muslims. The teachings have been taught in *pesantren* (Islamic boarding schools), *madrasah*, and some public religious meetings (*pengajian*) or in families. It has been durably reproduced then it embodied and has become a history of every individual *habitus* of Muslim, especially from the group of *santri*. As Bourdieu argues that “*habitus*, a product of history, produces both individual and collective practices in accordance with the schemes generated by history” (Bourdieu, 1990, 54)

Then, how much do the participants realize this process of bias toward normalcy and how does the process happen? Who are the actors, and what reproduces the concept of those with disabilities as being objects of charity? Generally, such views are promoted by Muslim society by the *Kyai* (clerics), *ustāz* (Islamic teachers) and Muslim

missionaries, as they espouse the concept that people with disabilities are weak and require help.

Those are elite people and middle class of *santri*, a group of Javanese Muslim practicing Islamic teachings. They have good educations which mostly receive in *pesantren* or *madrasah*. They have the access to Islamic books written in Arabic. They are raised inside very religious families, so despite of going to non-Islamic schools, they still practice Islamic-teachings very well. Some of them have become prominent businessmen who then donate their money to Islamic organizations.

Those are the people who materialize their perceptions on disability with establishing charitable institutions for people with disabilities and other activities related to disability. The fact shows, people behind the Islamic institutions concerning disability are from *santri* and have become the members of Nahdlatul Ulama or Muhammadiyah. *Madrasah*, *pesantren* and their religious families shaped their lives which are significantly determining their view on disability which has been materialized in establishing Islamic institutions and activities related to disability.

Following the Bourdieu's theory, the social background that they have such as access in education (cultural capital), knowledge on Islam (cultural capital), economic income (material capital), and network in Islamic community through NU and Muhammadiyah (social capital) led them in specific perception on disability. The 'objective homogenizing of group-*habitus* resulting from the homogeneity of the environment and specific conditions of existence is what enables practices to be objectively harmonized

without any conscious, intention, and calculation. It appears naturally in people's lives (Bourdieu, 1977: 80).

Their special institutions could also be pointed out as the party responsible for producing such ideas. All charitable institutions concerning disabilities in Yogyakarta are in fact, based on Islamic religious belief and some are connected to Islamic organizations and Muslim philanthropy. In short, they are the actors who practice activities that produce the concept of disability as object of charity.

Yayasan Bhakti Pertiwi is an institute concerned with disability, which was founded by Muslim philanthropists from Nahdlatul Ulama (NU), the biggest Muslim organization in Indonesia, and the management of this institute is also under Ma'arif NU Sleman, a semi-autonomous organization under NU concerned with education. One of its institutes, Bhakti Pertiwi, has founded a special school to accommodate people with disabilities, specializing in education for deaf people, autistics, and the physically disabled. Each of these are grouped based on their disabilities. Although some students come from outside of Yogyakarta, most are local, particularly in Sleman. In this school, students with disabilities are taught handicrafts, farming and planting trees. The school is founded under the auspices of NU, with financial and operational support by philanthropies through NU, NU-related networks and from the Social Welfare Department. Not merely giving material support, the philanthropists, NU and the government also provide programs and curricula that enable its operations.

This special school is likewise connected with several other special schools and organizations under NU as well as disabled organizations, particularly those under the

government. For many events, such as Ramadan or other Muslim holy days, the SLB often becomes a place to receive philanthropic donations. Clearly, Muslim organizations, with special schools and institutes, are significant actors for producing the concept of disability as an object of charity.

A similar case can be found with PCRM Muhamadiyah, a foundation based in the spirit of Islam, which teaches its followers to consider people with disabilities as other human beings. This foundation is built for missionary work, as they believe that taking care of people with disabilities is one way to promote Islam. The foundation focuses on blind people, and only blind Muslims can become members. Most members come from Muhamadiyah, the second biggest Muslim organisation in Indonesia, and most are from Yogyakarta, though some are not local but want to study in Yogyakarta.

Since this foundation is under the umbrella network of Muhamadiyah, and relies on philanthropic funding from Muhamadiyah, it operates under the management of Muhamadiyah and follows its philanthropic circle. Nonetheless, some of its programs are also supported through government funds. At this institute, blind people live in special dorms and are sent to special schools under management by Muhamadiyah. They receive special training on handicrafts, musical performance, and massage in order to prepare themselves for work in the real world after graduation.

This institute is likewise connected with other institutions, especially those linked to Muhamadiyah and other Muslim communities. For example, it is located very close to YAKATUNIS, the most famous Muslim foundation for blind people in Yogyakarta and one person participated in founding both of these organizations. It also has ties to the

government, Dinas Sosial (Dinsos), disabled Muslim organizations such as ITMI (Association of Blind Muslims in Indonesia) and PPCI (Union of Indonesian Disabled People), each of which are organizations of disabled people created by the government and Muslim philanthropic organizations.

YAKATUNIS (Yayasan Kesejahteraan Tuna Netra Islam) is a major Muslim institution concerning disabilities which must be taken into consideration by anyone who wishes to discuss disability in Yogyakarta. It was founded by a group of Muslim philanthropists in Yogyakarta, and takes care of blind people in the spirit of Islam. According to this institution, Islam is a religion that asks its followers to pay special attention to blind people. One of the founders of this institution is among the same group of people who founded PCRN. Initially, it was supported by wealthy Muslim individuals who had important role in Islamic organizations throughout Yogyakarta. Certainly, this institution has also received support from Dinsos programs. YAKATUNIS has special dorms for blind people, who were originally almost exclusively local, though recently there are residents from across Java. The organization has expanded as Yogyakarta has come into its own as a center of university studies, as many blind people come to study there.

Aside from receiving free daily food and free accommodations, residents at YAKATUNIS learn various subjects such as public speaking and reciting Koran. Moreover, they frequently also studied additional subject areas such as music performance and massage. Some of them are called on to sing at special events in the YAKATUNIS network or for personal networks of those who run the organization. Most



of them studying at Islamic schools and become members of ITMI (Association of Blind Muslims in Indonesia). In fact, a graduate of YAKATUNIS is the leader of ITMI.

The large Muslim organizations, such as Muhamadiyah and NU, are clearly significant actors in conducting activities relating to disability as an object of charity. As seen above, there are connections between Dinsos, Muslim organizations, Muslim philanthropists, organizations of disabled Muslims, and foundations concerned with disability. Members of these groups socialize together, share ideas and participate in organized activities together. Religion is a main reason for their social connections.

The main format for the treatment of people with disabilities in such organizations is to confine them to a specific place, namely, a school or dorm, where they are expected to receive specific training in basic career skills such as handicrafts, music, massage, and other life skills. Government participations in such programs extend and reinforce this pattern. We can see, then, that in Java Islam has formed a perception of those with disabilities as being “objects of charity.” Religious activities during Ramadan involve the giving of charity by Muslims who visit the disabled foundations or those who engage in fundraising for them.

According to Bourdieu’s theory, the discourse of disability as an object of charity is supported by a circle which, in Bourdieu terms, employs monetary capital and social capital to create networks and social connections that form the *habitus*. As Bourdieu stated that capitals are strongly determined the character of *habitus*, which is a product of the internalization of externality and externalization of internality. Due to this social network, members share ideas, internalize their concepts of disability, and then

externalize these views, which are subsequently articulated and expressed in various activities, as explored above: setting up special dorms and special schools, giving donations, providing training in certain skills, and so forth. The connections between Muslim philanthropists, organizations, and foundations are what drive the process of the *habitus* group in perceiving disability.

That process leads the perception of disability to become embodied and well-installed between them. Then, the activities related to disability are as Bourdieu (1977) once said “Produce the event or what they are its product” which means they are a product of the process which actually they produced. (Bourdieu, 1977: 82). Their social background, Muslim environment gear them to concept of disability which materialized in their activities. As Bourdieu has said

“it is constituted in the dialectical relationship between, on the other hand, a *habitus*, understood as a system of lasting, transposable dispositions which integrating past experiences, function at the very moment as matrix perception, appreciations, and action and makes possible the achievement of infinitely diversified task (Bourdieu, 1977, p.83).

This is one of the views on disability, expressed it Yogyakarta as a field of conflicting meanings of disability.

## **The Medical Model of Disability**

### ***Legacies of Colonialism***

Analyzing disability from the perspective of Western medicine was introduced to Indonesia through colonialization. The Dutch brought physicians to Java for their own

medical needs. After this, the Dutch East Indies Company systematically institutionalized the practice of Western treatment after building its fortress at Batavia in 1621. This was continued by the construction of the first Western hospital in Indonesia in 1626, a place for treatment of tropical diseases (Schoute, 1937: 27).

In addition to the colonialists, Catholic missionaries also played a significant role in bringing and implementing medical perspectives on disability. With the spirit of missionaries, they provided health care and nursing services to Javanese people.

During the governorship of HW Daendels (1762-1818), hospitals were developed rapidly across Indonesia to serve the needs of the military. He built many small hospitals in various regions, which were networked with each other to assist wounded soldiers and provide health care for the Dutch, as well as to control tropical diseases. Until 1820, hospitals were restricted from treating local Indonesians unless they received explicit permission to do so (Scortino, 1995: 56). As Scortino has argued, at that time, medical treatment was a military affair. In 1820, when the Dutch sent Prof. GGK Reinwardt to handle all health affairs in the Dutch East Indies, Reinwardt reformed the health care system so that it had a civil mandate (Scortino, 1995: 60). At that time, the government began opening civil hospitals, or *stadsverbandhuizen*, in Batavia for the first time. They specifically catered to the disabled, crippled and elderly, as well as the wounded, particularly soldiers (Scortino, 1996, in Boomgard, 1996: 24-29).

Medical vocational educations were not developed until the arrivals of Dr. JC Scherure 1893 in Yogyakarta, replaced by Dr. Pruys in 1906, and Dr. Borvoet in

Mojowarno, Jombang. Although they came to Java to handle health care, in Yogyakarta, they trained local nurses to take care of wounded soldiers. The first Christian hospital was built in 1914 (Scortino, 1995, 62).

During the Raffles, when the Dutch East Indies was occupied by England, medical systems developed across rural areas, especially as a response to smallpox outbreaks. This was the point at which the local Javanese shifted from traditional perspectives to Western perspectives on the treatment of people with diseases (Schoute, 1937: 110-37). For example, as illustrated in a novel told by Hans Pols, Nyonya Amile, a woman living at Yogyakarta, had already decided not to use traditional and herbal medicine nor to consult with a *dukun*, a person with supernatural power could heal the disease (Pols, 2009: 179). From this we can conclude that the process of colonialization took some time to change Javanese's perspectives on disability and health. These changes of perspective from herbal and traditional treatment to modern medicine, from the spiritual healing to medical healing, also changed Javanese perspectives on people with disabilities. The disabled were regarded as people who had supernatural powers prior to colonialism, but with the introduction of Western medicine, they came to be regarded as people having an affliction that must be cured.

Eugenics were also practiced by the colonials, which as Leonard J Davis said (1995) has argued played a significant role in "enforcing normalcy" and strengthening the discrimination against those with disabilities (Pols, 2010: 347-362 in Bashford and Levine, 2010). Psychiatrists and doctors conducted large researches projects in Javanese society which used them as the basis for establishing mental asylums. They defined

people having mental illnesses or mental disorders as abnormal. The first mental hospital was established in Bogor in 1882, the second in Magelang, close to Yogyakarta, in 1902 and later in Sabang, Aceh, in 1923 (Pols, 2010: 354-354 in Bashford and Levine, 2010).

One of the most influential psychiatrists at that time was FH Van Loon (1886-1971), who together with PHM Travaglino depicted natives as “childish, emotional, infantile and unreliable” (Pols 2010: 354 in Bashford and Levine, 2010). In his report, Javanese were described as displaying emotions at a rate five times higher than Europeans. Based on his report, eugenics organizations such as *Egeneische Vereeniging in Vereeniging in Nederlansch-Indie* were founded starting in 1927, a group which included biologists, doctors and psychiatrists supporting eugenic policies (Pols 2007:355 Bashford and Levine, 2010).

Doctors and psychologists also played a very influential role in treating people with disabilities. Some of them became advisors and managers for special schools established by the Dutch. In this process of establishing special schools, Christians also became involved, since they wanted to do charitable missions relating to their religious doctrines. The first special school in Indonesia was the school for children with visual impairment in Bandung, West Java, established in 1901. In 1927, another special school was built for the mentally retarded, and in 1930, the first school for the deaf was established<sup>4</sup>

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<sup>4</sup> Rochmat Wahab, 2005, “Country Report on Education Provisions for the Children with Intellectual Disabilities in Indonesia” available at: <http://staff.uny.ac.id/sites/default/files/penelitian/Rochmat%20Wahab,%20M.Pd.,MA.%20Dr.%20,%20Pro>

In Yogyakarta, the medical perspective on people with disabilities is closely linked to the role of Catholicism. In 1917, the Standard School was established as the first Catholic educational institution in Yogyakarta. Over time, missionaries then built a hospital for the Javanese as a charitable mission that provided services while teaching Catholic doctrine. In order to establish the hospital, the church in Yogyakarta leveraged its relationship with Boromeo at Maastricht Nederland's, asking for financial support from its congregation. On February 22<sup>nd</sup>, 1927, they established a foundation that would go on to complete the hospital, inaugurated by Mrs. CTM Schmutzer van Rijckevorsel on September 14<sup>th</sup>, 1928<sup>5</sup>

This hospital played a significant role in health affairs around Yogyakarta, as can be seen from support given by Sultan Hamengkubuwono VIII, who participated in the inaugural ceremonies. The Kingdom also contributed material support such as providing an ambulance. A few years later, the hospital opened several branches particularly in the rural areas around Yogyakarta. This is how the medical perspective on human health was introduced to Yogyakarta. The East Indies government and Christian missionaries equally played roles in establishing the medical perspective within Javanese society, a function that was later taken over by the Government of Yogyakarta.

This process is closely related to Dutch humanitarian ideas and policies concerning ethical politics. One pivotal impact of such policies was the modernization of systems for health and disability, including increasing infrastructures, irrigations,

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[f.%20/COUNTRY%20REPORT%20FOR%20INTERNATIONAL%20SEMINAR%20IN%20JAPAN%20\(R\).pdf](#) retrieved on August, 17, 2011.

<sup>5</sup> The history of this hospital could be found in its official website:

[http://www.pantirapih.or.id/index.php?option=com\\_content&view=article&id=68&Itemid=63](http://www.pantirapih.or.id/index.php?option=com_content&view=article&id=68&Itemid=63) retrieved on August 17, 2011.

provision of health care and educational opportunities for natives. Due to these policies, health care in the East Indies were improved steadily (Pols, 2007:173 in Mohone and Vaughan, 2007). One of ways in which this policy was implemented was through the establishment of STOVIA (School tot Opleniding van Inlandsche Artsen), or the School For Education for Indigenous Physicians in Jakarta (Scortino, 1995: 62), a medical school that produced many of the doctors who worked all over the East Indies, including Yogyakarta.

Those were the people who have become pioneers in perceiving disability in medical model. They were people who have been involved in medical affairs such as, physicians, nursing, and other medical people. They were people born in elite class having high access in modern education particularly in medical science which only view people in Indonesia were able to get it. Due to their education (cultural capitals), their environment (social capital), and their elitism (material capitals) they strongly become influential to the process of the production of medical model in defining disability “abnormality”.

### ***Perpetuating the Medical Model after Colonialism***

The colonial concept on medical model in analyzing disability has been perpetuated by rehabilitation center, hospital, medical science Gadjah Mada University and Dinsos (Department of Social Affairs) which are having great rules in producing the concept. It means the physician or doctors who, in fact, were born in elite family and got high access in education particularly in medical science. They are group of people behind the process of producing medical model in disability. Some of them are inspired

by Christianity which historically indeed had done many charitable activities related to disability in Yogyakarta. Those people, then, materialized their concept through many activities, programs, or establishing institutions concerned in disability issues.

One of these doctors from STOVIA was Suharso, a pioneer of rehabilitation for people with disabilities. During the struggle for independence, he treated Indonesian soldiers who were wounded or disabled, and he provided medical support for people near the front. In 1948, he was appointed as a doctor at a hospital at Jabres, Solo, to deal with surgery and disabled soldiers. When Yogyakarta became the capital of the Republic of Indonesia, the Dutch tried to reoccupy the city in 1948. Suharso employed nurses to take care of those with disabilities (Poliman, 1983: 40).

In 1946, Suharso established a center for rehabilitation to deal the problem of disabilities. He established a prosthetics center for those who had been physically disabled. This center would later play a significant role in rehabilitating the disabled due to the support of Suharto's government, when it became the biggest center of rehabilitation for people with disabilities in Indonesia, and eventually it served as a reference for all rehabilitation centers, including those in Yogyakarta.

Due to Yogyakarta's proximity to Solo, some patients with disabilities went to Solo for rehabilitation. Nevertheless, Panti Rapih, a hospital in Yogyakarta, also treated the disabled locally. A separate hospital for the blind, Rumah Sakit YAP, was established in 1923 by an ethnically Chinese doctor who had been trained in the Netherlands. Eventually, it established a program to teach braille to the blind.



In 1950, Dr. Suharso was appointed as the Minister of Health Affairs during the Sukarno era. As minister, he was keen to ‘medicalize’ the treatment of the disabled in all regions across Indonesia (Poliman, 1983: 85-86). From a medical standpoint, being disabled was thus classified as “abnormal” nationwide, and people with disabilities were thereafter considered abnormal within society (Bernes and Mercer, 2003). Therefore, Suharso was the important person in producing and implementing medical model of disability.

Influenced by Suharso’s medical perspective on disability, the Indonesian government believed that to be disabled was a type of social pathology. Eventually, disability issues were reassigned from the Ministry of Health Affairs to the Department of Social Affairs, grouping the disabled with other people who are considered to display social pathologies, including prostitutes, transvestites, and beggars (*Kompas*, September 13, 1965). In this context, Suharso was a person establishing the basic principle of medical model seeing disability in Department of Social Affairs (Dinsos).

Before 1982, the disabled in Yogyakarta were generally rehabilitated in Solo; throughout the 1970’s, most of the disabled people who were rehabilitated in Solo came from Kulon-Progo (*Kompas*, May 28, 1976). In Solo, they received treatment in a special dorm and were trained in handicrafts, sewing, sculpture, and other skilled crafts.

Nevertheless, Yogyakarta is one of the cities that has stood at the forefront of applying the medical perspectives to the issue of disability throughout Indonesia. In addition to the presence of Panti Rapih, there is also a department of medical science at Gadjah Mada University, the oldest university in Indonesia. Because of this , Yogyakarta

is seen as one of the leading cities in Indonesia for medical development. For example, being chosen as the host city for the Special Olympics in 1978 highlighted Yogyakarta's leading role in disability affairs. Many disabled people from all over Indonesia came to participate in various sports, including badminton and track events (*Kompas*, October 19, 1978).

The government began to establish special schools for the disabled in 1968, and Yogyakarta has many such institutions, only to being behind Bandung and Solo. In 1970, there were 41 disabled students and teachers (*Kompas*, December, 10, 1970). In addition, in the 1984, the government built SLB C, a special school for the mentally disabled, which has likewise served as a model in this regard for other institutions.

In collaboration with departments of psychology and faculties of medical science, the government has established many special schools to centralize the treatment of people with disabilities (*Kompas*, July 5, 1984). Indeed, Yogyakarta became so overwhelmed by an excess of teachers for such special schools that the government deployed them to rural areas and private institutions.

A hospital affiliated with Protestant congregations was also founded on November 16<sup>th</sup>, 1982, by Colin FA McLennan from New Zealand. This center for the disabled is called Pusat Rehabilitasi YAKKUM (Christian Center of Public Health Rehabilitation Center), more generally known as YAKKUM. With his colleagues, and supported by a Christian hospital, McLellan built the rehabilitation center with the support of the Association of Presbyterian and Methodist Churches of New Zealand and by the Union of Churches in Indonesia. To operate its programs, YAKKUM was

originally supported by Bethesda Hospital. However, as of June 1<sup>st</sup>, 2004, YAKKUM was spun off from the Bethesda system.

YAKKUM focuses on rehabilitation and vocational training for the disabled, including physiotherapy, occupational therapy, medical clinics, prosthetics, education, psychosocial counseling, and vocational training, as well as community-based programs. Each of these programs are intended for the disabled in Yogyakarta, although some provide services to people who are not local. Typically, people with disabilities are placed in a dorm, where they receive training to shape their capabilities to live in society, including tailoring, wood carving, sewing, computers, and handicrafts. In cooperation with hospitals and Dinsos (The Department of Social Affairs), YAKKUM also works on community projects for rehabilitation, skill trainings, and rural projects.

According to the government, people with disabilities are regarded as abnormal people. They define the disabled as those who have “abnormalities” “deformities” and “oddities” in their bodies or senses. Moreover, special treatment for such patients is seen as necessary since they are not like normal people. Such a perspective on disability is in line with what Collin and Mike Olive, Geof Mercer and Tom Shakespeare and others adhering to the social model school of thought call the “personal tragedy approach,” namely that being disabled is interpreted as a type of physical or sensory impairment belonging to someone, so the identification of those who are or are not disabled is the responsibility of medical professionals (Bernes, Mercer and Shakespeare, 1999: 26).

In addition, the government uses the legitimacy of medic to classify children with disabilities, which is decisive in determining their placement in special schools.

Currently, there are 26,173 people with disabilities in Yogyakarta who are classified as physically disabled, blind, psychotic, retarded, deaf, or multiply disabled. Such a classification is of course conducive to the smooth operation of training programs and other policies, though from Foucault's perspective it implies a "politic of governmentality" (Foucault, 1991).

Dinsos participates in handicrafts training and has donated sewing machines for people with disabilities. Some such programs are conducted directly with those who have disabilities, but other training programs are cooperative efforts with special schools and Islamic foundations concerned with disability issues, including YAKKUM. Dinsos also provides donations of funds to support programs to special institution providing a dorm for disabled. For example, in 2009 the government built a rehabilitation center for the disabled as a response to survivors of the 2006 earthquake. Initially, the center was designed by the Yogyakarta Provincial Department of Health Affairs, the Faculty of Medical Science at the Gadjah Mada University Medicine, the Hospital of Dr. Sardjito, YAKKUM, as well as with support by the World Health Organisation (WHO). In total, the government spent 58.6 billion Rupiah, and the rest of the funds were provided by international agencies. The new center is quite large, accommodaing 1,297 patients.<sup>6</sup> The rehabilitation program of this center took YAKKUM as its reference, with programs duplicated from YAKKUM. Currently, it has expanded to serve not only people with disabilities but also others who are considered as displaying "social pathology," such as beggars and street children.

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<sup>6</sup> The information of this center could be found at <http://jogjanews.com/2009/05/28/gedung-rehabilitasi-penca-pasca-gempa-bantul-diresmikan/> retrieved August 18, 2011.

Based on this elaboration we conclude that the main actors producing the medical model in perceiving disability are still people in medical affair and their inner circles. They are an elite group who have access to medical science which historically established by the Dutch. From this exploration the physicians and people having been involved in medical affairs are the party responsible of the treatment of medical approach to disability. This group of people is really influential in government policies toward people with disabilities. Not only taking over rules in government programs, they also the main actors producing medical model if disability amongst society.

Following Bourdieu's theory therefore supported by their modern education, their class-position, and their networks les them how to see disability. As stated by Bourdieu the background and history rules significant to the *habitus*. The concept has been steadily internalized and externalized among them. (Bourdieu, 1977: 72, 83) due to the similar condition and experiences, all members of group constitute the precondition for all objectification and apperception' (Bourdieu, 1977: 86)

The table shows the government budget spent for disability affairs, the budget are spent for special schools, rehabilitation programs, institunalisation of people with disabilities and such as policies which are based on medical analysis. It shows how strong the medical model is influencing governmental policies related to disability issues.

Term is a way of producing disability from the medical perspective. The production of disability as an "abnormality" involves apparatus that include special schools, medical institutions and rehabilitation centers, which receive support from private institutions such as YAKKUM, Islamic institutions concerned with disability,

charitable missions, and organizations of people with disabilities. In addition, the term for “disabled” in Indonesian serves as an epistemic foundation that reinforces the concept of normalcy and positions those with disabilities as a group of abnormal people.

Analyzing the government’s budget spent for people with disabilities (shown in table 5, we can see the orientation and perspective of the government’s policies. The budgets issued by the government show allocations for programs based on the perception that people with disabilities are abnormal people.

Governmental expenditures spent include those for rehabilitation programs, handicraft training, donations for special schools, and cooperative programs that involve dorms for the disabled and rehabilitation centers. Not even a meager sum of money is budgeted for implementing equal rights, access, or promotion of the rights of people with disabilities.

Based on what has been explored above, we can take a conclusion that each of these actors is basically an elite person who is based on medical education or related to medical affairs. Following Bourdieu’s theory, *Habitus* is, therefore, a shared body of durable dispositions, classificatory categories and generative schemes as a product of history. (Bourdieu, 1990, 54). Their background such as education and economic condition are determinant to their idea and concept of disability, which later on materialized in establishing institutions, activities or programs through government where they have significant rule.

**Table 5: Government Budget for the Disabled by Region<sup>7</sup>**

Regions	Programs	Amount (Million Rupiah)	
		2006	2007
<b>Bantul</b>	Donation for people with disabilities out off “panti” (dorm).	10	
	Operational Donation for Special Schools	20	24
	Donation for Students at Wiyata Bakti Special School	1	2
	Donation for teachers at Wiyata Bakti Special School		27
	Donation for PERTUNI		2
<b>Gunung Kidul</b>	Donation for SLB	23.5	
	Empowerment for People with disabilities after Earthquake	40	43.5
	Empowerment and stimulant for 9 <i>Panti</i> and 4 SLB	7	120
<b>Kulonprogo</b>	Donation for SLB	17.5	
	Donation for People with Disabilities Rehabilitation programs	50	42.364
<b>Sleman</b>	Donation for PPCI (People with disabilities Association)	15	
	Giving of vocational training	25	
	Donation for Veteran Disabled	2	
<b>Yogyakarta</b>	Rehabilitation	312.75	216.3

<sup>7</sup> This data is adapted from a paper written by Wasingatu Zakiyah and Nurul Assaadah Andriani, 2008, *Advokasi anggaran difabel: Menuju anggaran publik yang berpihak kepada difabel perempuan* (Budget advocacy for disabled: Toward public budget for woman disabled), Yogyakarta: Unpublished manuscript

In consequences, the government agencies, charitable foundations, rehabilitation center, and other organizations, conspire to produce a view of disability that adopts the medical perspective, seeing disability as an abnormality. The Dutch introduced this point of view, which is indeed a colonial legacy for Indonesia. Hospitals and rehabilitation centers, since the colonial era, have typically been supported by the government and charity institutions.

Along with the shift of people's perspectives from traditional cure and supernatural medicine to modern medical cures, people's perspectives have also changed gradually from seeing disability as a type of "super-neutrality" and a special power, to become instead a type of "disease" or a thing that should be cured medically. This shift of Javanese perspective has affected on how the treatment of disability have taken place.

Following Bourdieu's theory, this perspective is reproduced continually, internalized and externalized within society. Supported by various forms of capital, networks (social capitals), power (symbolic capital), and material capital from both non-government and governmental sources, people in Yogyakarta have absorbed this perspective. It has been durably structured within everyday life, and thus it has been established in the *habitus* that influences both governmental policies and daily life.

Social capital has been formed here between medical institutions, rehabilitation centers, and governmental agencies such as special schools. Dinsos, private foundations concerned with disability issues in which place the disabled in special dorms, and governmentally sanctioned organizations for those with disabilities. Each of these actors



forms bonds of mutual support for sharing experiences, concepts, programs, funding and other corporative efforts related to disability.

This medical perspective is reproduced and externalized within what Bourdieu calls the “undisputed opinion,” the perspective of the broader community, which is then absorbed by individuals (Bourdieu, 1977: 170). Due to capital support, the perception and durability of externalization and internalization has become a way of life for the populace, an “undisputed opinion” which is very influential in governmental policies and people’s everyday lives when they think about disability. It is simply taken for granted that the disabled should be recipients of charity, and many educational and work institutions require applicants to be “mentally and physically healthy” (*sehat jasmani rohani*), which further segregates “normal” from “abnormal” members of society.

### **The Social Model and the Rights Model**

In 1970’s there were high surges scholarships offered from developed countries such USA, Australia, Netherland, Germany, etc. as a portrait of that in 1973 there were 350 people studying in Russia. Mansour Fakih was one of the Indonesians studying abroad; he pursued his master and Ph.D. at University of Massachusetts, USA in critical education.

Mansour was really well-known as an intellectual organic in Indonesia. He was a person spending his time thinking on social justice such as gender, labors, economics, farmers, and so forth. He had a good connection in international NGO particularly those

that stood on left wing, and also established many NGOs and connected many NGOs in Indonesia in order to make strong social movement for social justice.

He was a pioneer giving effect in analyzing people condition with disabilities most of them being segregated, and regarded as “abnormal”. In 1997, he was the head of Oxfam Indonesia, granted him large networks particularly with people who were involved in NGOs, this situation enabled him to solicit information on social issues from the field more than other people.

Shortly, he and Setyadi Purwanta have traveled in many areas and communities to see the condition of people with disabilities. Setyadi was a blind involved in NGO concerning disability issues, before becoming a blind, he was an activist of NGO concerning on human rights and democracy. With Setyadi and other disabled activists, they promoted a new perspective on disability. They concluded that the most significant impact on people with disabilities was that they are segregated and discriminated against, and there existed a belief within all of society that people with disabilities are “abnormal” people (Purwanta, 2004: 23 in Suharto and Munandar 2004).

### ***“Difabel” as a Deconstruction***

Inspired by social movements in other countries, namely the social model movement in UK and the independent living movement in US, and supported by the new democratic system in Indonesia, these activists proclaimed that the term itself, “disability,” is a condition produced by the dominant capitalist system, which leads members of society to compete with one another. To deal with this problem, the concept

of disability should be deconstructed, and the term “disability” should be done away with, as “normal society” aims to oppress the disabled.

In Indonesia, people with disabilities have been called *penyandang cacat* which means, “people with disabilities.” In Bahasa Indonesia, *cacat* refers to a negative situation, either “not perfect” or “wounded.” The underpinnings of the new attitudes and policies questioned this term for people with disabilities, since “dis” means that a person “does not have capability to do something.” Therefore, the movement advocated changing the term to “difabled” or, in Indonesian, *difabel*. According to these activists, the new concept is that everyone is capable, and every person has his or her own differences. Changing the term would imply a change in the policies and attitudes, with the prevailing view more democratic and equitable. Promoting the new term for people with disabilities is, actually, promoting new paradigms, new attitudes and new policies (Purwanta, 2004: 41-73 in Suharto and Munandar 1994).

The first NGO to use the social model in seeing disability is Dria Manunggal, an NGO led by Setyadi Purwanta and supported by Mansour Fakih. According to Dria Manunggal, Being disabled is caused by social oppression or the “ideology of normalcy.” As mentioned on its website:

“Disability exists since inequitable power system runs such disabling process. The process is done through social construction both structurally and culturally by labeling, treating, conditioning, positioning those social groups who have different ability as disabled people. Applying the term of “difabel” (an acronym of differently-able-people) was not merely replacing the term of disabled people at all...In reflecting to such circumstances, in 14 November 1991 a non-profit organization called DRIA MANUGGAL, was established. (Driamanunggal, 2010)

Based in Yogyakarta, Dria Manunggal has become the center of a growing movement to use the term “difabel.” Many people have become involved in this NGO, some of them as interns and others as volunteers to gain experience and knowledge of disabled rights and human rights, and to work toward creating an inclusive society.

After deciding on the use of this new, more democratic term, activists worked hard to promote it. University campuses were key places they focused on to further the rights of the “difabled.” In 1998, Dria Manunggal, an NGO led by Setyadi Purwanta, declared that “difabled” was the new term to refer to people with disabilities. Other NGOs, including PPCI, PERTUNI (Union of Indonesian Blind People), GERKATIN (Indonesian Deaf Movement), BPOC (Indonesian Disabled Atlets), FKCPPTI (Front for Phisically Disabled People), YAKKUM, LBH (Legal Aid Institute) and other groups in Yogyakarta used the new term as well. They declared that the equal rights of people with disabilities should be implemented as part of the surge of democracy that occurred during the post-Suharto regime (*Kompas*, Juny, 23,1998).

The political situation in Indonesia helped this movement. After over throwing down the authoritarian regime that had been in place for 32 years, in 1998, Indonesia made a significant transition to a democratic political system. It was a time when many social groups and civil organizations took advantage of the opportunity to voice their concerns. People within the disabled rights movement thus argued their case and promoted their causes. Due to the more democratic conditions, NGOs that were concerned with the rights of the disabled took the opportunity to promote the concept of

the new term, “difabel.” They also organized people with disabilities to convince them that people with disabilities are actually just as human as other people.

In December 1998, some of disabled rights’ activists who were associated in KAPCI (Committee for Indonesian People with Disabilities) met together and created a dialogue titled “Reformatting the Indonesian Disabled Rights Movement.” These groups recommended using the new term for people with disabilities. In May 1999, in Yogyakarta, Mansour Fasih and the head of PPCI approached one of the biggest universities in Indonesia, Gadjah Mada University, to hold a conference on disability perspectives, and to elaborate on the effect of the term “dis” in disabled life while introducing the new term “difabel” to scholars (*Kompas*, September, 29, 1999)

### **Promoting “Difabel” as a Way of Promoting Human Rights**

Since 1998, many disabled rights activists have been committed to applying and promoting this new term, which would help the disabled gain greater acceptance within society. Due to the groups’ commitment, they used the term “difabel” in their daily lives, official correspondence, and other activities. In addition, they promoted the new term throughout Indonesian society.

Dria Manunggal was an NGO that had a pivotal role in disseminating the deconstruction of the concept of disability. Some of the disabled activists involved in this NGO were interns, while others were full members. Many of them went on after gaining this experience to establish new NGOs with the same missions and perspectives. However, some of the activists also became embroiled in internal conflicts, and they

broke away to create new organizations, such as SIGAB. For those coming from outside Yogyakarta, some returned to their home cities to form new organizations, such as Interaksi and Talenta, both of which are in Solo, and Puskota, based in Surabaya.

Those organizations have been built by fortunate disabled who come from middle class families and have the capability to access university education. Some of the elite of SIGAB, for instance, graduated from western countries' universities. It means the actors of producing the "disability" are people who are well-educated and have first-hand experience of disability or have relatives with disability.

Their educations, environment, and relationship among NGOs activist, along with their disabilities are history determining their *habitus*. Following Bourdieu's theory such as background could be capital determined their *habitus*, as he stated In so far - and only in so far - as *habitus* are the incorporation of the same history, or more concretely, of the same history objectified in habitus and structures" (Bourdieu, 1990: 58) Due to the similar condition and experiences, all members of group constitute the precondition for all objectification and apperception' (Bourdieu, 1977: 86). And they materialize their views and ideal type of society for people with disability in their NGO and organizations they participated.

SIGAB, a disabled rights' organization based Yogyakarta, is one of organizations that actively promotes the new term. Moreover, they use the term "difabel" in their name SIGAB, or *Sasana Integrasi dan Advocacy Difabel* (Center for Integration and Advocacy of the Difabeled). They publish a quarterly magazine, which is also available online, as well as a book to serve as a tribute to disabled rights' activist Fakhri. They also publish a

weekly bulletin, which is distributed to NGOs, official government organizations, and cultural centers.

Meanwhile, to promote the rights of people with disabilities, SIGAB, CIQAL, ITMI, PERTUNI, Dria Manunggal, and other such organizations hold what they call “Sunday morning gatherings,” held every Sunday morning in downtown Yogyakarta. During this event, the organizations promote the discussion of the rights of disabled and how to include the disabled in society. In this gathering, they use and promoted the new term for all people attending the meeting. They invited artists, government officials, academics and so forth to gather in 2000. Other programs coordinated by SIGAB which promoted the new term “difabel” included movie screenings on campuses. These films persuaded the students to become involved in the disabled rights movement.

SIGAB is an organization created by a former associate of Dria Manunggal. Through this process, some of SIGAB’s members also created new organizations, or were involved in other groups. Those organizations are concerned with the same issues, yet they do not share the same focus. For example, Matahariku is an organization for the hearing impaired. It focuses on deaf rights, sign language and multiculturalism. This organization was influenced by SIGAB’s mission statement, and the founder was a member of SIGAB. Some of SIGAB’s functionaries likewise became members of Matahariku. This paralleled what happened within the DMC (Difabled Motorcyclist Community.) DIFA Karya is another organization that is concerned with economic empowerment for people with disabilities, again established by SIGAB members.

Many organizations have been created with a specific focus, since they know what should be done to fill the gaps for the disabled. SIGAB is such an organization concerned with advocacy. SAPDA is concerned with the empowerment of people with disabilities. Matahariku's focus is on the culture of the hearing impaired. Karya is concerned with economic empowerment. The DMC is concerned with disabled culture and transportation rights, which also supports participation in civic events, such as parades and carnivals, working to make them accessible for disabled people.

Based the table below, we can see that there are many social organizations, such as Dria Manunggal, which have their own foci. They are promoting and deconstructing the medical concept of disability which was first worked on by Dria Manunggal. Additionally, these groups practice activities based on the "difabel concept", such as advocacy, accessibility, promoting the culture of the hearing impaired, and economic empowerment. The social movement of Dria Manunggal has continued in the paradigm of inclusivity. They have not only deconstructed the paradigm of segregation and exclusivity, but they continue to struggle to promote the rights of people with disabilities.

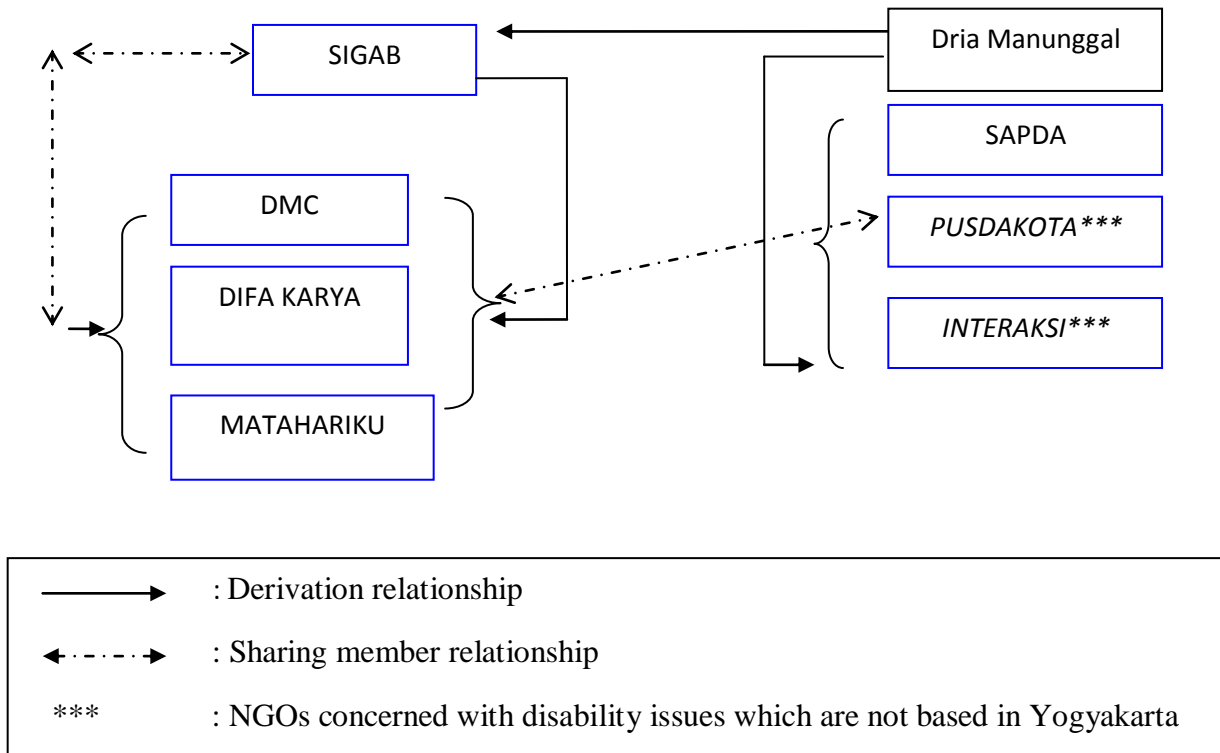
There have been various activities created by those within the disabled rights movement to promote the term "difabel" throughout Yogyakarta. These activities could be characterized in the following ways: (1) *Persuasion* in which a group or individual works to persuade others to believe that people with disabilities are equal, and that the appropriate word to call them is therefore *difabel*, not *penyandang cacat* or "disabled." (2) *Parades and performances* (for Independence Day, Disability Day, etc.), including a large parade that used to be held to celebrate International Disability, as well as carnivals,



pantomimes, theater, music, and disabled motorcyclist parades. (3) *Advocacy*: For example, opposing a presidential election which banned disabled people from participating as candidates in 2004, advocacy for accessible busses, for reform of university admission policies, and protests against cases of discrimination involving the disabled. (4) *Publishing*: including bulletins, magazines, blogs, and movie documentaries to promote their idea on disability. (5) *Organising and Empowerment*: convincing people with disabilities themselves to form groups and organizations to train each other in human rights issues. Some of them have gone on to create programs related to disability issues in their communities.

Internal conflicts exist within these organizations in terms of getting resources, achieving transparency and selecting leaders. For these reasons, they have generally been divisive, fragmented and at cross-purposes. However, these conflicts tend to have beneficial effects in terms of the development of new paradigms for which these groups struggle. Although many disabled rights organizations have been fragmented, this disunity does not make them incapable of changing people's mindsets and implementing a new paradigm that is more democratic. Therefore, disunity and dissension within the disabled rights movement has actually expanded the new paradigm, which was their original goal. These internal conflicts and disunity do not always weaken the social movement. In fact, dissension can breed and cause change.

**Figure 5: The Disunity of *Difabel* Movement**



On the other hand, the presence of these organizations strengthens their identities and makes them feel part of the same struggle. Thus, the formation of the *habitus* group processes here works with disunity, like the binary fusion of a biological organism. Internal conflicts contributed to the process of identity expansion. In sum, “difabel” as an identity was formed by the process of disunity and the dissemination of information. Like living cells, these organizations developed by splitting themselves. This was done through the use of the term “difabel.” The word has become a symbol for people who believe that disability is a social construction that is produced by social oppression. The moniker also is a symbol of struggle for the new paradigm.

The identification of people as difabel was also determined by the specific moment when disability issues became a topic of public discussion, namely, discrimination during the general election in 2004 against Abdurrahman Wahid, a former president and a visually impaired person, as the KPU (Committee for General Elections) did not permit him to run due to his blindness, as there is a rule stating that candidates should be in good health mentally and physically. The Indonesian Physicians Association became involved and had to provide an official medical statement regarding the “sickness” (*Kompas*, May 22, 2004).

These protests were a momentous occasion and had tremendous effect on the disability rights movement in Indonesia. Disability issues became a topic of serious public discourse. Many seminars and public discussions were held on campuses talking about how to define disability, as well as the rights of the disabled. In addition, on May 7, 2004, there was an advertisement in the second biggest newspaper in Indonesia, the *Java Post*, saying: “How wonderful their contribution in the world: Franklin D Roosevelt, John F. Kennedy, David Blunkett, Stephen Hawking, Ludwig van Beethoven, Taha Husein, Marla Runyan, and Abdurrahman Wahid” (*Jawa Pos* May, 7, 2007). Each of these historical figures were disabled people. At the time, disability was a word that came to be debated by many people, and the term “difabel” spread across the country. Many dialogues and public discussions were held on campuses, and on television, regarding the rights of people with disabilities. In sum, disability became a topic of public discourse and the term “difabel” was a popular buzzword.

At the same time, NGOS and people with disabilities united and recognized themselves in unity. The term “difabel” became a symbol unifying them and strengthening their spirits to struggle for equal rights for disabled people in Yogyakarta. It was at that time that they called themselves “difabel.” It also happened that most NGOs concerned with equal rights began using the term as well. The disabled had previously been forgotten by many human rights organizations. Clearly, the general election of 2004 was a decisive moment for people with disabilities, when many people were introduced to the concept of disability as a “social construction;” that is, that disability rights are human rights. It was also the time that the definition of disability was contested by the medical approach and social model. It should be pointed out here that Mansour Fakhri and Setyo Adi were two people who pioneered the introduction and promotion of the social model or rights model in seeing people with disabilities.

The social capital that is formed between these NGOs connects them with each other. Some of their leaders have personal friendships formed during internships and worked at Dria Manunggal. Dria Manunggal, indeed, has a great role creating and connecting activists in the disabled rights movement.

They have made networks between them, they share their idea on the ideal type of society and paradigm on disability, funding, information and so forth. Shortly, their historical background and dream of society for disability and the fact of people with disability in Yogyakarta lead them to the same perception on disability. It is then steadily structured in their daily-lives and activities, they internalize and externalize it which is subsequently embodied their *habitus*, Bourdieu said “ the habitus, at every moment,

structures new experiences, in accordance with the structures produced by past experiences, which are modified by the new experiences (Bourdieu, 1990: 60)

Subsequently, they have displayed similar concepts and missions for disabled rights. After establishing these NGOs, they collaborated in advocacy for several discrimination cases in Yogyakarta. Despite their various focuses, most of them are know each other, have the same ideas and team up to voice the rights of people with disabilities.

Bourdieu once stated that social capital can determine the formation of a “habitus group.” Supported by the social networks between them, the concept of disability emerges as a “social construction,” which is then reproduced among them. With material capital from international funding agencies, they advocate their concept through their programs. The new concept is circulated among members until it is discussed and believed as truth.

Regarding their backgrounds, networks, and opportunities to meet up and share their ideas and programs, members of these organizations have therefore created a “habitus group” that shapes their views and perception on disability. This perception has been expressed among the larger community in Yogyakarta. The perception that disability is a social construction and that being disabled is due to social oppression has been slowly embodied within the lives of Yogyakarta in general, and it has shape popular responses to government policies on disability.

**CHAPTER IV**  
**CONTESTED CONCEPTIONS OF DISABILITY**  
**IN GOVERNMENT POLICIES**

This chapter describes the various contested conceptions of disability, as described briefly in the preceding chapters, with specific focus on governmental policies. As argued in the previous chapter, four conceptions of disability operate within the discursive field of Yogyakarta. One way to see this contestation is to analyze how people view government policies relating to disability. Below, we consider how such contestation has occurred in four separate policies relating to health issues, education, and public services for the disabled.

**Contested Concepts of Health Policies for the Disabled**

Nearly all disabled people in Yogyakarta have insufficient monetary income and live below the poverty line. Due to the comparatively low levels of education that they receive, many are unemployed and dependent on their parents and families for support. This condition is disastrous when such disabled people become ill or suffer an accident. Meanwhile, middle class and wealthy families normally can afford to purchase accident and health insurance for their children.

Many important things necessary for the health of those with disabilities are not recognized in related health policies. In addition, special needs such as assistive devices like corsets and hearing aids, high doses of vitamin A, and therapy for paraplegia or

cerebral palsy are not listed at all in the government's health security scheme (Andriani and Zakiyah, 2007). Moreover, health facilities and services provided by the government are unreliable when it comes to recognizing disabled people's needs. Access infrastructure such as ramps, braille signs for the blind and other essentials for accessibility are unavailable, particularly in rural areas. Many public health facilities, such as *Pusat Kesehatan Masyarakat* (Center for People's Health) or Puskesmas and other health services centre also lack proper accessibility for people with disabilities. This is largely due to the fact that the government has not yet issued any comprehensive regulations that would set a legal foundation for accessibility in health services.

National and local health services financing schemes thus fail to reach the disabled, even in basic regulations, and the disabled are a most vulnerable population since they are largely poor. Although there is a national regulation on protecting people with disabilities, including the provision of health services and access, it has not yet been adopted in local areas, where there is a lack of specific rules regulating health access for people with disabilities.

There are two primary governmental systems for financing health security. One type of health security is known as the *Askeskin* (*Asuransi Kesehatan Masyarakat Miskin*, or Health Insurance for the Poor) program. In 2008, this program was changed into the *Jamkesmas* (*Jaminan Kesehatan Masyarakat*, or Public Health Security) program, which is managed by the Central Government via the Ministry of Health, in cooperation with PT Askes, a health insurance company belonging to the government. The second type of system is handled directly by the regional government and is known as the

Askesda (*Asuransi Kesehatan Daerah*, or Regional Health Insurance) system, but in Yogyakarta this system is called the Jamkessos (*Jaminan Kesehatan Sosial* or Social Health Security) system.

However, there are problems regarding to these health policies. At the national level, the Askeskin program often did not provide services that reached its target group, due to high levels of corruption and a culture of collusion, whereby most of its funds went to benefit those who are categorized as middle class rather than the poor. This was the case because many people in positions of responsibility in this system took benefits for their own sake. Moreover, the quota system implemented at the provincial level for the Rukun Tetangga (Basic Unified Administration) or RT does not clarify who in society should be classified as “poor,” and more precisely it does not specify the disabled. Compounding on this, many health facilities such as hospitals, particularly private hospitals, are reluctant to accept patients on the government health insurance program, since reimbursements from the government insurer have a terrible reputation of delay and bureaucratic red tape. Due to the complexity of reimbursement procedures and the problematic way in which data processing is conducted, a large number of the disabled can not access the Askeskin program (Andriani, and Zakiyah, 2007: 30)

Similar to what happens at the national level, the local *Jamkesmas* program also does not recognize people with disabilities as a group of stakeholders, mentioning only that health security aims to serve poor people, without mentioning people with disabilities as part of that group. In fact, some people with disabilities are economically not very poor. However, if they fall ill, they can easily slide into poverty due to the



overwhelming cost of health care. In addition, it is likely that people with disabilities will have their own specialized health care assistance, when basic health care is what is actually needed.

Clearly, people with disabilities do not enjoy equal access to the health care system, nor to health insurance programs, and they have not benefited from equal protection of the law in this regard. The health care needs of persons with disabilities are not covered in government subsidized health insurance programs, thus leading to exclusion on the basis of disability. Where health services are available to the general population, they are typically inaccessible to persons with disabilities due to physical barriers and communication barriers.

The health conditions of people with disability is reported in a survey done by the UCP Indonesia and Ford Foundation (2010), showing that 47.8% of people with disabilities in Kulon Progo live with no access to health care. In Gunung Kidul, 52.8% such people lack such access, and in Bantul, fully 78% of people with disabilities have no access. Likewise, in Sleman, 72.2% people with disabilities lack access to health care. Yogyakarta is quite better quite than Gunung Kidul and Sleman in this regard, as a slight majority (52%) of people with disabilities have such access.

**Table 6: People with Disabilities and Health Security in Each Regions**

	<b>Kulon Progo</b>	<b>Sleman</b>	<b>Bantul</b>	<b>Gunung Kidul</b>	<b>Yogyakarta</b>
Having Access to Health Care	52.2%	27.8%	22%	47%	52%
Lacking Access to Health Care	47.8%	72.2%	78%	52.8%	48%

Clearly, the condition of health care for people with disabilities in Yogyakarta does not yet fulfil the ideals of the CRPD (Convention of Rights of People with Disabilities). At both the national and the regional level, health security policies should elevate people with disabilities to the same position as normal people. Currently, they are still a subordinated group in the terms of their rights of access to health.

Due to this situation, several NGOs involved in the disability movement have advocated and struggled for equal rights for people with disabilities in health issues. SAPDA (the Centre for the Advocacy of Women, Difabled [Persons with Different Abilities] and Children) is an NGO that is very keen on health-related advocacy for the disabled. It was established in 2005 with a vision to realize inclusiveness in all aspects of social life to ensure protection of the basic rights of women, the “difable,” and children in education, health and employment on the basis of equal human rights.

According to SAPDA, and echoing the general opinions of NGOs concerned with disability in Yogyakarta, people with “disabilities” should instead be described as having “different abilities” or *difabel*. Due to discrimination against this group, they are marginalized within society, and they are only disabled to the extent that oppression exists within society. One such source of discrimination is in health care policies which, SAPDA argues, are based on the government’s assumption that the disabled are “abnormal” people, implying that health services for people with disabilities should be under the management of Dinsos. As such, health care policies barely recognize people with disabilities (Andriani and Zakiyah, 2007).

SAPDA has engaged in a variety of initiatives to advocate for equal rights to health care for people with disabilities. For example, they have organized people with disabilities in Yogyakarta to educate them about their rights. Two significant organizations of people with disabilities that were established through such programs are *Paguyuban Penyandang Cacat Sleman* (Association of Persons with Disabilities in Sleman, or PPCS) and *Persatuan Penyandang Cacat Kulonprogo* (Union of Persons with Disabilities in Kulonprogo, or PPCKP). SAPDA has also organized people with disabilities in Bantul, including in Bambang Lipuro, Jetis, and many other villages affected by the 2006 earthquake that hit Yogyakarta and Sleman. These organizations aim to unite people with disabilities in one voice to struggle for their right to equal access for health care.

In addition, SAPDA has given workshops to build the capacities of the disabled in general. The first of these workshops focused on enhancing technical capacity, addressing the capacity of the disabled to be self-reliant. The second focused on strategic capacities, namely the enhancement of their capacity to undertake in advocacy at the local and national levels for the fulfilment of their fundamental rights.

In these capacity building programs, advocating for the fulfilment of fundamental rights, SAPDA collaborated with IDEA in organizing budget training activities in Klaten, Sleman and Yogyakarta City at the end of 2005. Upon the completion of this budget training, SAPDA and the communities/organizations of the disabled at the municipal and city levels moved forward in advocacy for fulfilment of the rights of the disabled in health care and budget allocation for the disabled in Yogyakarta's annual provincial and municipal budgets.

Much of the process of organizing and building the capacities of the disabled were supported by “local wisdom” as collective social capital. An example of this is the traditional position of the disabled in society, particularly in rural areas, where it is still common to believe in the traditional Javanese cosmology that positions people with disability as extraordinary and powerful people in society.

Various programs aiming to elevate people with disabilities from subordination within modern society to receiving the support of such communities, because they recognize that the disabled should not be isolated and neglected when it comes to health issues. Moreover, Javanese cosmology and beliefs lead them to view disabled people as privileged in a certain way. Health in general is a big issue within Javanese culture, and a common greeting would be *piye kabare, sehat?* (“How are you, are you healthy?”). Being healthy is an important measure of happiness for Javanese people. The health of the disabled is even more important in traditional Javanese culture, as people with disabilities standing at a privilege position in Javanese cosmology. Thus, one of the major reasons for success in these capacity building projects is the leverage of existing social capital in traditional Javanese society.

A second strategy applied by SAPDA is to develop advocacy networks; to ensure availability of resources in lobbying government officials responsible for handling health security and convince them that health care for the disabled should be a specific topic of policy. Such lobbying targeted Bapeljamkesos, the agency in charge of implementing health care across the province of Yogyakarta. In this case, SAPDA has been also

advocated for special provisions for the disabled in hospital and other public health facilities, including the provision of special access for the disabled.

SAPDA has also worked to build awareness among people with disabilities who work in the government, as well as those who are disabled and live at home with families rather than staying at special dorms or private religious institutions. In doing so, they inform others of the needs of the disabled in terms of health care and government programs. This campaign was supported by many institutions, as well as NGOs concerned with disability, and organisations of disabled people in Yogyakarta. SAPDA sent a recommendation letter, based on original research, to government officials and stakeholders concerning the ideal type of policy that should be done on health care for the disabled (Andriani, 2008).

Regardless of the difficulties and the long struggle for equal health care rights of people with disabilities, SAPDA met with a great deal of success in its programs, including rallying 1,573 disabled people in efforts to secure explicit health security allocations from the Yogyakarta provincial government. After this lobbying, the health care budget for disabled people was increased and other among things. In this case, the SAPDA succeeded in advocating for the provincial budget to be more sensitive to the disabled and to protect the basic rights of the disabled as written in the Convention of Rights of People with Disabilities.

The case of SAPDA leads us to conclude that the government perceives the disabled as an “abnormal group” which is subordinated under other people. This concept, an ongoing problem, is contested by the competing view that is raised by SAPDA and

other NGOs to conceptualize disability as a social construction. Indeed, SAPDA is rather avant-garde in Yogyakarta in arguing that nobody should be referred to as “disabled,” since everybody has different abilities, and that people with disabilities have the same rights to health care, just like other citizens.

The conflict between these two views is a case in which there are conflicting *habitus* groups, namely, one for people within government and another for people within the social movement. People within the government, based on their background, environment, and social networks, have their own *habitus* that guides their concept of disability. On the other hand, people in SAPDA, as described above, have their own connections with people in other NGOs. Their background and networks confirm their perception that the disabled are entitled to equal rights with other people. Disability is thus contested in its meaning, and consequently the policy on health care for people with disabilities is a field where differing *habitus* contest to define it.

As described above, health policy in Yogyakarta could incorporate Javanese concepts and culture more by engaging the local wisdom of Javanese people, namely, that health is a measurement for the human condition, supporting the position on health advocacy taken by SAPDA and other NGOs. In fact, Javanese perceptions stand in opposition with government policies, as the *habitus* of Javanese people is strongly congruent with the concepts of NGO activists who wish to change government policies. In sum, the Javanese concept of disability together with the social model of disability conflict with the medical model adopted by the government.

## Contested Concepts in Education

In Yogyakarta, it is very difficult for people with disabilities to have access to education, since nearly all educational institutions from the grade school level to universities are inaccessible to them. Typically, they are either sent to special schools that cater specifically for those with disabilities, or they receive no schooling at all. Moreover, the governmental budget for the education of the disabled and general lack of assistive technology exacerbates these problems.

The current policies are derived from the same Dutch colonial legacy that brought modern medical practices to Indonesia. Currently, many educational institutions and workplaces require applicants to meet certain health conditions including being “mentally and physically healthy” (*sehat jasmani rohani*). This requirement segregates those with disabilities, who then lack equal rights to education as enjoyed by other citizens.

To illustrate the situation of education for the disabled, in the Temon sub-district of Kulon Progo, there are 290 people with disabilities having access to education while the remaining 29.31% do not. In the urban area of Margansan sub-district of Yogyakarta City, there are 195 people with disabilities, of which 146 received education and 49 of them did not. In rural areas, people with disabilities are generally less well educated than in urban areas (Mudzakir, 2010).

Instead of including people with disabilities in public schools, the government has built hundreds of special schools for people with disabilities. People with each type of disability are separated from “normal society” in schools where they receive training in skilled work such as sewing, carving, and painting. These special schools (*Sekolah Luar*

*Biasa*, or SLB) in Yogyakarta include: 1. SLB-A for children with visual impairment; 2. SLB-B for children with hearing impairment; 3. SLB-C for children with developmental disabilities; 4. SLB-D for children with physical and motor disabilities; 5. SLB-E for children with social and emotional disorders; and 6. SLB-G for children with multiple disabilities. Each of these are further classified, based on the level of school, as TKLB (Special Kindergartens), SDLB (Special Elementary Schools) SLTPLB (Special Middle Schools) and SMALB (Special Senior High Schools), as explained in the table below.

**Table 7: Special Schools in Yogyakarta by Region**

Regions	No. of Schools	No. of Students				Total Students	Total Classes	Total Teachers
		TKLB	SDLB	SLTP-LB	SMA-LB			
<b>Bantul</b>	16	181	585	157	85	1,008	293	157
<b>Gunung Kidul</b>	6	34	196	52	39	321	125	47
<b>Kulon Progo</b>	7	29	147	13	3	192	96	44
<b>Sleman</b>	23	129	549	147	105	1,020	317	163
<b>Yogyakarta</b>	8	48	202	115	73	438	130	67
<b>Entire Province</b>	60	484	1,679	511	305	2,979	961	478

A survey done by the UCP (United Cerebral Palsy ) Indonesia, supported by the Ford Foundation (2009), shows that only 18.8% of people with disabilities in Kulon Progo have gone to school, while 81.2% have not. For those who are attending school, the survey shows that at Kulon Progo 76.9% of people with disability are going to special schools and 23.1% of them are going to public schools. In Gunung Kidul, only 20.8% of



people with disabilities are going to school and 79.2% of them are not. For those going to school, 63.6% are going to special schools and 36.4% attend public schools. In Bantul, just as is the case in other regions, only 28% of people with disabilities who have received education while fully 72% of them have not; of those going to school, 92.9% are going to special institutions and 7.1% attend public schools. In Sleman, unlike the other regions, the survey shows that 44.4% of people with disabilities are going to school and 55.6% of them are not; for those attending school, 58.3% go to special schools and 41.7% go to public schools. Again unlike other regions, 84% of the disabled in Yogyakarta City attend school and only 16% do not, though 95.2% of them are going to special schools and merely 4.8% are in public schools.

**Table 8: Summary of Access to Education for the Disabled in Yogyakarta by Region**

	<b>Not Attending School</b>	<b>Attending School</b>
<b>Kulon Progo</b>	18.2 %	18.8%
<b>Gunung Kidul</b>	79.2%	20.8%
<b>Bantul</b>	72%	28%
<b>Sleman</b>	55.6%	44.4%
<b>Yogyakarta City</b>	16%	84%

**Table 9: Types of Schools Attended by People with Disabilities**

	<b>Special Schools</b>	<b>Public Schools</b>
<b>Kulon Progo</b>	76.9%	23.1%
<b>Gunung Kidul</b>	63.6%	36.4%
<b>Bantul</b>	92.9%	7.1%
<b>Sleman</b>	58.3%	41.7%
<b>Yogyakarta</b>	95.2%	4.8%

The institutionalization of people with disabilities, which is practiced by government and strongly supported by Islamic teaching, is clear in the field of education in Yogyakarta. Almost all charitable foundations established for the disabled are based on Islamic ideals and, as described in the previous chapters, they are funded by Muslim philanthropists and large Muslim organizations such as Nahlatul Ulama and Muhammadiyah. Programs based on Muslim values generally establish special dorms for people with disabilities, where the disabled are given vocational training. The perception of those foundations are that weak people need help and, as such, the disabled are often the object of giving alms in Islamic rituals. Clearly, for those who establish such institutions, the disabled are an object of charity, and this concept is strongly congruent with the government's existing programs.

In response, NGOs have struggled for equal rights for the disabled by establishing advocacy programs that criticize the government's policies on education for the disabled and work for equal rights for people with disabilities in the field of education. They have also organized protests against discriminating involving people with disabilities. These protests are often scheduled to coincide with international days of celebration for the disabled or in response to specific cases of discrimination against disabled people. Attendees at the protests criticize discriminatory policies and inaccessible educational facilities. While protesting to make education more inclusive, some NGOs or disabled people have advocated using Javanese culture and local wisdom in order to get the public's support.

On December 3 2009, for instance, disabled people who were members of the *Forum Persatuan Difabel Bantul* or FPDB (Forum of Union of Disabled People in Bantul) held a rally working on the main street at Bantul, where they demanded accessibility in educational facilities for the disabled. In this demonstration, the disabled brought dolls and puppets of *Punokawan* (Kedaulatan Rakyat, December, 10, 2009). They believed that by doing so, they could attract to the public and they would be supported by them. A similar event occurred on January 16, 2010, held by an alliance of disabled people in Yogyakarta including NGOs and the FNAD (Front National Anti-Discrimination), which held a demonstration to protest a discriminatory rule from the nation's biggest university. In this protest, they also used the elements of *Punakawan* and the spirit of local wisdom to convince the stakeholders in the university to make more accommodations for disability rights.

Dria Manunggal is an NGO keenly concerned with promoting inclusive education for all people, concentrating on disability issues in Yogyakarta. It was established in 1991 as the first NGO that was not based on charity and that adopted the social model in its view of disability. As explained above, based on the foundational work done by this NGO, many disability activists came to adopt the critical and social model perspectives, eventually establishing their own NGOs that also focused on the social model perspective.

Dria Manunggal was involved in the process of evaluation of government regulations concerning disability, namely, *Undang Undang No. 4 Tahun 1997*, the first written policy issued to accommodate the rights of people with disabilities, which many

NGOs recognized as still based on biases in favor of “normal” people and those not able to accommodate the rights of people with disabilities. In 2000, supported by international funding, Dria Manunggal established a model of inclusive schools for where all children could join in classes together. The goal of this program was to make inclusive education a model at the national level. Years after this program, many schools have taken the school established by Dria Manunggal as a model for inclusive education. Likewise, in 2005, Dria Manunggal was mandated by the government to draft a law regarding the implementation of inclusive education at Yogyakarta. Some of the contents of this draft law were already used by the provincial department of education affairs, and since its creation, it has subsequently become the main policy regulating inclusive education in Yogyakarta.

Dria Manunggal also lobbied stakeholders in government to implement equal rights for people with disabilities. Through seminars, dialogues, workshops, and publications, they promoted inclusive education throughout society in Yogyakarta. They have also monitored inclusive education institutions that were already established. This NGO has also been involved in many protest actions involving cases of discrimination of people with disabilities in education.

Like Dria Manunggal, SIGAB is another NGOs that promotes the rights of people with disabilities; it was founded by members of Dria Manunggal and advocates especially for equal rights for people with disabilities in education. One program undertaken by SIGAB was meant to assist in the learning process for children with disabilities, used in regular classes in public schools in Kali Gatuk, Piyungan Sendangsari Dlingo, Bantul.

The result of this program was that there is now a positive image of people with disabilities in education within the general population of Dlingo, with people in that area now willing to put their children with disabilities into public schools instead of isolating them in their homes.

Programs conducted by SIGAB have promoted inclusive education in various ways. One of these was to begin dialogue at many campuses in Yogyakarta to promote accessibility in education. They also did seminars, as well as movie screening at campuses and senior high schools. Due to these efforts, some educational institutions have worked to become more inclusive, and several universities have attempted to become more accessible for the disabled. Nonetheless, most public schools are still not accessible and do not accept students with disabilities. The result is still quite far away from the end result envisioned by NGOs that demand equal rights at all schools. Nevertheless, although the rule proposed by NGO demanded that all institutions of education should be accessible, the regulation as it was adopted only mandates that each regency or town must appoint at least one elementary school or junior high school in every district to be inclusive.

**Table 10: Types of schools in Yogyakarta**

	<b>Special Schools</b>	<b>Inclusive Schools</b>	<b>Public Schools</b>
National	2,627	640	191,422
Yogyakarta	59	62	5012

This situation currently does not address the problem of people with disabilities in education, since many of those with disabilities in rural areas still lack proper accessibility. Aside from this, there also remains the problem that, by appointing one school as inclusive, the disabled will still be centralized and segregated at that school. As a consequence, there is a belief that schools appointed to be inclusive see decreasing enrolment as people believe that inclusive schools are bad schools, which is why people with disabilities get in. Many schools do not wish to be designated as inclusive schools, since they are afraid that such a requirement would decrease its quality of education, while many schools in Yogyakarta are competing with each other to be the best schools.

From the above, we can see how the contestation of disability concepts has occurred in government policies on education. The policy of segregating people with disabilities in special places, based on the kind of disability, is a policy derived from the medical model that assumes that the disabled are abnormal people. In Foucault's terms, the owner of the power employs this "politics of governmentality" to engage in controlling, classifying, defining, and managing based on the kind of disability. The policy has been responded to by people in NGOs who perceive disability as a social construction. People with disabilities are people having the same rights as other citizens. Moreover, every educational institution should be accessible for all people and should not discriminate against anyone, whether disabled or not.

These NGOs have created their own world of discourse, establishing what Bourdieu calls a *habitus* group, determining their perspectives on disability and education. As people in NGOs and people in government also have their own

backgrounds, circles, knowledge, education, and so forth, such factors are capitals that form *habitus* groups which are very significant for establishing perspectives of disability in education. Furthermore, education for the disabled here is a field of contestation where many *habitus* groups try to define the terms in question, namely, the *habitus* of people in NGO versus the *habitus* of people in government.

From this contestation we can understand how, with regard to education, Javanese cultures benefited NGOs in their struggle to implement the rights of people with disabilities in education. Elements of Javanese cosmology were likewise used by disability movement activists to convince people that discrimination against people with disabilities is not a part of Javanese culture. Furthermore, the Javanese conception of disability in this case supports the social model and conflicts with the medical model implied by the government. Meanwhile, the government policy to institutionalize people with disabilities is supported by Islam, which recognizes the disabled as objects of charity.

This process of contestation can be seen in the uneven implementation of the programs for people with disabilities. The demand for inclusive educations has been responded to by the government but, due to the strong dominance of the medical model, and of course due to technical problems, the social model is not fully supported by current policies. Based on the values inherent in basic human rights, which support the social model, all schools should be accessible and open for the disabled since they are public spaces, and public places must by definition accept all people. However, the government has so far only designated certain schools as inclusive school, leading to a

contestation between two conceptions, namely, and disability as a social construction versus a conception of disabled as abnormal people.

There are 62 inclusive education and public schools, in 2009, while there are 5,012 public schools overall; clearly, then, the struggle of the disability movement to obtain equal rights for people with disabilities is really still far and long. What has been achieved in the past decade, nonetheless, is a revolutionary change from the colonial legacy. The presence of schools that are not accessible and people's assumptions that inclusive education is not good in quality shows that how acute the domination of normalcy is within society in terms of education.

Clearly, the narration of education for the disabled displays a contestation between the social model and the medical model. Javanese culture stands with the social model in promoting equal rights for people with disabilities in education. Nonetheless, the medical model is still dominant.

### **Contesting Concepts of Disability in Accessibility for Public Facilities**

One of the most significant elements of life for people with disabilities is accessibility in public spaces. With accessible public spaces, people with disabilities have the mobility to fulfill their daily needs. Accessibility is a basic and profound need, and ignoring accessibility for the disabled has a significantly detrimental effect on the lives of people with disabilities.

Yogyakarta, generally, is a city where public spaces still do not meet international standards on accessibility for the disabled. Most public services, such as traditional markets, office buildings, banks, mosques, churches, parking places and other areas are



not accessible and do not following universal design standards. In addition, public services and special facilities needed by the disabled are not available. For example, signs telling the name of a building, room or road are still rare, though such simple matters are extremely useful for the deaf. Braille signs and maps showing location and direction are also rare, so the blind do not have access to go where they desire. Indeed, even braille symbols telling the location and building names in public spaces are barely ever found, and audiovisual cues, important for the deaf, are absent in transportation stations and other public facilities.

In Yogyakarta, almost all sidewalks, except for some key places, are inaccessible to wheelchairs and blind people. There are no ramps and guiding blocks for the blind, which situation is exaggerated by the bumps and hole in the sidewalk that bother even non-disabled pedestrians. In Java, people with disabilities are not able to access traffic lights and other signs that are much needed for the disabled. Therefore, blind people must ask others to help them to across the road. The disabled often encounter difficulties accessing roads, since there are no accessible bridges for pedestrians to cross the road.

Public transportation, including air, sea and land, is likewise inaccessible. For sea and land transportation, most facilities are not accessible to wheelchairs, as is the case for buses and trains, where people with disabilities find it difficult to board. Some buses are not even willing at all to take a disabled person as a passenger. Discrimination against the disabled also happens on transportation services; for instance, disabled people must sign off on special agreements that airlines will not be responsible in case of any accident occurring to a disabled person within an airplane cabin. Thus, despite the fact that

disabled people pay the same prices for their flights as do any other people, they are not guaranteed equivalent standards of safety. Meanwhile, pilots, drivers, stewardesses, ship captains, and other transportation professionals are not aware of these issues.

Some people with disabilities solved their transportation problems by using modified three-wheeled motorcycles. However, before 2008, the government officially did not admit such modification of vehicles. In addition, most parking areas in Yogyakarta are not friendly to those with disabilities, as special parking for the disabled is rare, and with a modified motorcycle, it can be difficult to find appropriate parking.

Such conditions for public services have a significant impact on people with disabilities, many of whom find it impossible to attend college, especially those coming from rural areas, due to the inaccessibility of transportation that would bring them into the city. Many disabled people are not able to find work and fulfill their daily needs, since transportation and public facilities are not accessible. Unlike developed countries, where many disabled people find it easy to navigate the public sphere, it is rare to see disabled people in public spaces such as museums, malls, markets, post offices, and so forth. Clearly, due to the lack of accessibility in public facilities in Yogyakarta, the disabled are forced into an impoverished life, isolated from society, and lacking the educational opportunities afforded to other citizens.

Meanwhile, the government does not recognize accessibility as a significant issue, since stakeholders and policy makers are not aware of the needs of those with disabilities. They instead believe that it is possible to build special facilities for them, since the population of disabled people is small compared to the number of non-disabled people.

They further argue that the installation of access infrastructure would be inefficient, since it would not be used by the disabled. Accessibility would be very costly, they say, and it is not a primary concern for public services. Given the government's perspective, we could conclude that such attitudes are clearly normal-biased, perceiving the disabled as abnormal people who are only a handful of people, and thus unworthy of attention.

Following the logic of statistics, people with disabilities are marginalized, and those who are not common or normal have no need to be accommodated in public spaces.

According to J Davis, this situation is one of "enforcing normalcy." (Davis, 2000)

For disability movement activists, the social model is closely connected to their ideology and perception of accessibility and disability issues. In the social model, disability is a social construction. Due to the existence of an environment that is not accessible for the disabled, they become isolated from many activities, including social, economic and political events, and thus they become a group that is oppressed by society. In the view of the social model, being disabled is a fact of social oppression caused by an inaccessible environment. Therefore, the environment is the cause that makes people become disabled, not the person.

Because of this perception of disability, those who believe in the social model, such as members of Dria Manunggal and the Center for Universal Design and Diffability at Gadjah Mada University have advocated for accessibility for the disabled in public spaces. Both of those institutions are the first to promote accessibility for the disabled in Yogyakarta. With support from international funding, they are pioneers in pilot accessible areas, located at Malioboro, and therefore called the Malioboro Project. This is

a pilot project that now serves as an example of accessible places for the disabled nationwide, and could serve as a model for many other regions wanting to make accessible public spaces for the disabled.

Some who promote accessibility for public places engage in a variety of actions such as publishing, demonstrations and protests, seminars, and dialogues in addition to lobbying the government and policy-makers to make accessibility part of the official laws. Furthermore, all NGOs concerning disability are promoting accessibility as one of their core missions.

In 2001, for instance, only 0.3% out of a survey of 35 building regarded as public facilities are accessible to the disabled (*Solider*, 2006 January and February) Since that time, many new buildings have been built to be accessible, as awareness is higher now, though construction codes have not been adjusted for the disabled. Some of the inaccessible buildings include regional legislative assembly buildings, city hall, the provincial legislative assembly, Tugu train station, Giwangan bus station, Plaza Ambarukmo, Adi Sucipto airport, the *Guiding Block* on Malioboro street, Mangkubumi and Ahmad Yani streets, the Keraton palace, the Jogjakarta Expo Center, Taman Pintar (a park for children), the Melia Purosani Hotel, the Hotel Hyatt, the Gabusan Art Market, and Batu Stadium at Bantul, all of which are major public sites (Bayo and Agustin, 2006) Many buildings of higher education institutions are gradually being renovated to install accessibility infrastructure for disabled people, though such efforts are not really based on the official standard of accessibility. For instance, the building of medical science in Gadjah Mada University, building of dentistry science, building of agro-industrial

science, farm faculty, and other buildings at Sanata Dharma University, and National Islamic University of Yogyakarta, have each been recently renovated to try to accommodate accessibility for people with disabilities.

As mentioned in the previous chapter, there is also a new law on the issuance of driving licenses for the disabled. On December 10, 2008, the central provincial police in Yogyakarta released the directive *Surat Nomor B/4965/XII/2008/*, signed by all of chiefs of police, admitting people with disabilities to apply for driving licenses. Based on this law disabled people are now lawfully able to drive their modified motorcycles.

Dria Manunggal and the Center for Universal Design established a model for accessible areas in Yogyakarta with their Malioboro Project. Malioboro Street, in the center of Yogyakarta, is an icon of Yogyakarta and a significant cultural area belonging to the province. By making it accessible for the disabled, the intent is that it would raise the status of the city in a way that would invite other areas to copy the model. They believed by this model would inspire people throughout Yogyakarta and even Indonesia.

In this program, many institutions, NGOs and scholars were invited to be involved to in making Malioboro, a downtown street, as accessible as possible for the disabled. In addition, other stakeholders were invited including vendor communities and communities of people working for parking and for government agencies. They agrees to use Malioboro as a model accessible area for all people, including people with disabilities, and agreed to maintain accessibility infrastructure such as ramps, signs, and guiding blocks.

Meanwhile, SIGAB is an NGO that is very keen on promoting accessibility for the disabled. At 2006, for instance, they pioneered in advocating accessibility for new buses operating throughout Yogyakarta. These buses, called Trans-Jogja, are the most important transportation channels within the city. The advocacy included demands for ramps at bus stations, special seats for the disabled and voice signals for each stop for the blind. These efforts done by SIGAB and other institutions are certainly not failures, but it is hard to say they were successes either, since ramps were installed at the bus shelters, but there are still no ramps for boarding the buses from the shelter, and wheelchairs still require lifting to get in or out of each bus. Several ramps installed at these locations were too steep for wheelchairs, with slopes that fail to follow the standards issued by the government. There are also cases where ramps are blocked with bushes, piles of detritus, and water in places such as Gembiraloka, Jl. KH Ahmad Dahlan, and Jl. Brigjen Katamso. Clearly, the accessibility infrastructure installed at Trans-Jogja is still hit or miss, and do not adhere to existing laws on accessibility.

Problems also arose during the course of these NGO programs, including clashes with traditions and local cultures. As described by Inge Komardjaja, the barrier-free environment program proposed thus far in Indonesia have failed, particularly the Malioboro Project. In his study, Komardjaja focused on the Malioboro Project, which, according to her, failed because people in Yogyakarta are not aware of what is a properly accessible infrastructure.

For Komardjaja (2001), culture and communality and traditions of people in Asia, particularly in Java, are the culprit why such programs are not working. Javanese society

is family oriented, so people in Yogyakarta prefer to pay people to bring their children to school or other places. For this reason, they are unlikely to allow their disabled children to go out alone to public places, and thus accessibility provided for the disabled is barely used. With this communality and beliefs on disability and supernaturality, Javanese people are not aware of accessibility issues. They think that, if they were to allow their children with disabilities to go out, and something happened with them, people would blame the parents, particularly Javanese culture. Due to this cultural gap, there are many public facilities installed for the disabled, which are not used, and in some cases are occupied by street vendors. Even some disabled people themselves are unaware of the function of accessibility.

As for Trans-Jogja, most bus stations are still not accessible for the disabled, though SIGAB and many others continue to engage in advocacy. In addition, many of the ramps are used by vendors, especially during Ramadan. Apparently, such program is aiming to make transportation more accessible clash with traditional beliefs on disability and Javanese communality. Generally, they are willing to help the disabled within the confines of Javanese communality, and thus further attention for accessibility is seen as unnecessary.

Based on the above discussion, then, we can conclude that there are contested concepts of disability within government policies on accessible facilities and services for the disabled. As is the case with other policies, recognizing the disabled as “abnormal” is still become the foundation on which new regulations are formed. The disableds are not a majority, and so it is considered inefficient to make things accessible for them.

Government officials believe that the problem lies with the people with disabilities themselves, not with society as a whole and certainly not with the current state of public facilities.

Such perceptions generally are believed by people in government positions, and these perceptions durably structure society, which gradually embodies such views among people in government, its stakeholders and the general populace. People in general come to take for granted the ideal of the “abnormality” of the disabled, which then affects further policies on building, public facilities, and so forth. Nonetheless, there is another perception that disability is a social construction, a product of society. Due to the environment and social structure, people become disabled. Since inaccessibility presents a barrier to people, making them disabled, it is unjust not to make public facilities accessible, such that everyone can access them equally and there would be no “disabled” group. The backgrounds of disabled people, including their education, as well as networks between NGO activists, bias them toward a habitus group that affects their behavior and beliefs.

This contestation has been strong in Dria Manunggal’s programs to make a model of action and confront the concept of disability proposed by government, that is, to confront the medical perspective on disability. SIGAB, likewise, advocates an idea of accessibility that was previously never conceived by the government and the unserious manner in which infrastructure was installed for Trans-Jogja, followed by the protests, shows how this contestation plays out. Thus, there are two contesting paradigms between disability as a social construction and disability as a personal tragedy.



From this, we can see how urban planning and design policies are a field of contested *habitus*. Due to their background, the associations, and their forms of capital, both activists and people in government performed their *habitus* groups, which subsequently affect their perceptions and policies on disability. The same occurs in NGOs concerned with disability. Their backgrounds, including education, associations, and network likewise create their *habitus* groups, which have a pivotal impact on their perceptions of disability and urban planning. The city, in this context, is a field of contestation between *habitus* groups.

We have also seen above how the Javanese concept of disability has become a significant obstacle to the success of accessibility programs. In the contexts just discussed, education and health policy, Javanese conceptions support programs applied by the social model, but in the context of the accessibility infrastructure it is the opposite of the social model concept of disability. The Javanese have their *habitus*, and therefore they do not accept infrastructural accessibility, since based on Javanese cosmology being disabled is extraordinary and such people should not be left alone to their own devices in public areas. Referring to the basic concept, accessibility means individuality, which means, based on the independent living principles, people with disabilities should be allowed to service themselves without the other's help, so this is actually a process of "individualizing" disabled people.

Accessibility is actually a concept of western society in treating people with disability and, as is well known, western society values individual liberty, in contrast with Javanese society which prefers to be family oriented and thus rejects accessibility as an

important part of their life. According to traditional Javanese values, allowing the disabled to live individually would not be acceptable, since they are special people who should be taken care of every day. In the context of accessibility, then, the Javanese concept of disability sides with the medical model and against the social model.

In short, in city design there are contesting conceptions of accessibility and urban design in Yogyakarta that constitute a struggle between the social model and the medical model. In this context, the Javanese concept of disability, together with medical model, contrast with the view that accessibility enables individual lives for disabled people. As for the Islamic concept of accessibility, it is underspecified, implicitly supports the medical model since it views people with disabilities as objects of charity.

### ***Doxa, Hetrodoxa and Orthodoxa: The Contesting Concept of Disability at Yogyakarta***

*Habitus* is neither determined by structure nor the product of free will, yet it is an interplay between both structure and agency as they work durably. The *habitus* is formed, created and reproduced unconsciously, and it works without any conscious concentration as it is steadily internalized and externalized. The *habitus* is "...Embodied history, internalized as second nature and so forgotten as history ..." and its position is already absorbed and deeply adhered to within every individual or source of agency (Bourdieu, 1990: 56). Regarding this, Bourdieu asserts that *habitus* is a determinant of how a locus of agency can engage in "an organizing action," as a "way of being" becomes a "habitual state" and propensities for action (Bourdeiu, 1977: 214). Thus, *habitus* is a source of

objective practice, yet itself it is a subjective generative principle produced by the patterns of social life. It serves as the basis for what Bourdieu called a “matrix of perceptions, appreciations, and action (Bourdieu, 1977: 83).

Bourdieu defines *habitus* as: “a product of history, [which] produces individual and collective practices—more history in accordance with scheme generated by history” (Bourdieu, 1990: 53). In addition, Bourdieu has argued that *habitus* is also a foundation for producing collective actions (Bourdieu, 1990: 54) This means that every individual expresses his or her ideas, actions, perceptions and appreciation of reality, and then homogenization occurs between each of these. The durability of structuring structures becomes a collective *habitus* or class *habitus* (Bourdieu, 1990: 54; Bourdieu, 1977: 86). The group or class *habitus* is shaped by collective phenomena that reflect the group members’ durable adaptation, conformity and adjustment (Bourdieu 1994: 132), which is why various societies have differing cultures, opinions, and so forth.

Related to *habitus* and *capital*, by which Bourdieu goes beyond Marxism in defining capital as simply material. As has been described in the first chapter, Bourdieu extends the definition of capital into social capital, cultural capital, symbolic capital and material capital. Those types of capital are always determinately related to the *habitus*, which is a product of the internalization of externality and the externalization of internality. For example, people from the wealthy class will reproduce their cultures, in which capital is a fundamental thing involved within the process of cultural reproduction. In addition, capital embodied in agency can structure the scheme of actions, matrix perceptions and actions.

Related to these is the concept of *field*, that is, a space where different aspects struggle for power and where these aspects meet each other. Fields are social spaces in which agents or structures operate and express themselves. In this structure, the distribution of capital commands access to specific profits that are at stake in the field by their objective relationships to other positions. As such, capital is a factor in determining the *habitus*, since it is embodied in personality which would significantly determine the scheme of actions, matrix perceptions and actions. The capital would be very significant for *habitus* to face the field. It is a space where various competing *habitus* exist and meet each other to define something. The field is a space of contestation where many *habitus* compete with one another in defining something. Capital plays a significant role, since it determines the *habitus* in their competition, furthermore, and there is a dominant *habitus* that defines the dominant discourses, opinion, value and preferences. For Bourdieu, the dominant discourse is called *doxa*, which is absorbed steadily and then strongly embodied on every locus of agency, eventually becoming a truth that could not be interrupted. On the other hand, orthodox is an opinion supporting *doxa*. There is also *heterodoxa* which is a discourse trying to stand in opposition to a dominant discourse.

Following Bourdieu's theory, we could see how the different discourse of disability has developed from competing *habitus*. Every *habitus*, due to differing social backgrounds, enables different perceptions and practices on disability, and every *habitus* group performs differently with various opinions. As discussed in chapter three and above in this chapter, the view of disability as abnormality is supported and produced by the medical model. This opinion has already become a "truth" adhered to and embodied

in people's daily lives in Yogyakarta. Thus, disability as abnormality has become *doxa*, produced and supported by the medical model and in many cases by Islamic perceptions as well.

On the other hand, following Bourdieu's theory, every discourse has been produced by a *habitus* group. For Javanese people, disability is an extraordinary and magical thing, and therefore people with disability are extraordinary and magical people. This perception is durably reproduced in history of the Javanese people, and the concept of power in the Javanese kingdom supports and perpetuates this concept. Many rituals expressing such perception become practices representing how they perpetuate and reproduce, and externalize and internalize the concept which is implicitly embodied in people's day-to-day lives. Yet, it is difficult to point out the definite actors who express one opinion or another, since Javanese culture has absorbed this *doxa* as a whole. However, people in rural areas tend to more to believe in such traditional Javanese conceptions.

The same has happened with Indonesian Muslim conceptions of disability. Islamic conceptions of disability see people with disabilities as an object of charity. This concept has been produced and supported by Muslim people and organizations such as NU and Muhammadiyah, a charitable foundation, Muslim philanthropists and, in some cases, government. They produce this conception by building special dorms or schools placing the disabled based on their kinds of disabilities as a practice of their idea on disability. In addition, these places become spaces for charitable donations for Muslim philanthropists. Actors make networks, and stakeholders are connected to each other, so

that they share their ideas, money, programs and so forth. This web then works for reproducing the *habitus* group that determines the discourse and practices related to the treatment of disability.

The medical model's perception of disability as abnormality was introduced by the colonial Dutch. Initially it was meant to serve wounded soldiers, but this was expanded by religious missions, charitable activities, Catholic teaching institutions, and colonial and political powers and ethics. People involved in medical institutions such as Panti Rapih Hospital, YAP Eye Hospital, YAKKUM, and people in government are the main actors producing, supporting and perpetuating the "abnormality" of disability. They are connected to each other and they share their ideas on disability program, and consequently they produce their *habitus* group. Their backgrounds, such as their education, networks, and jobs, are very significant in shaping their arguments and perceptions on disability. The conception has over time become dominant within society, since it has been supported by the power of government within its practices and the implementation of policies.

In opposition to the medical model, the social model recognizes disability as a product of social oppression. It has been produced by activists, disability movements and NGOs concerned with disability who have studied critical social theories. They are strongly connected with each other. NGOs such as Dria Manunggal, SIGAB, and others have been making associations for sharing ideas, arguments, and programs related to disability. With these connections between them, shared capital, and backgrounds, they

have made their own *habitus* group which strongly impacts their idea that disability is a product of social oppression, and thus it determines their practices related to disability.

Each of these *habitus* contests for different meanings of disability. Disability in Yogyakarta is a field of contesting ideas to define the term, which can be seen in government policies on disability. Based on differing arguments and opinions on disability, each opinion came from its own *habitus* group, trying to respond to governmental policies. In many policies on disability, the groups express their opinions on how to treat people with disabilities. The various responses to government policies express the contestation of *habitus* in the field, namely, policies on disability.

For the three government policies on disability discussed above, it is clear how this contestation occurred. On governmental policies on health security, the government recognized people with disability as a group of “abnormal” people. This conception has been absorbed within society, and thus has become a discourse that is difficult to be interrupted. Three policies on disability above are really expressing how the abnormality of disability so becomes a truth, or *doxa*. Generally, most of policies are biased in favor of “normal” people. Most government health care programs and policies in Yogyakarta do not recognize people with disabilities as part of for their target stakeholders. The situation was responded to by disability movement activists who recognize disability as a product of social construction and social oppression. The activists’ programs apply the social model and support the concept of disability in Javanese culture, perceiving disability as a special and magical person. The presence of the disabled among them is

strongly significant and plays a fundamental role in maintaining the communality and the cosmology of Javanese society.

The concept of disability as an abnormality, produced and supported by the medical model, is still strongly dominant in government policies on health care. One of the pieces of evidence for this is that, in Yogyakarta, most people with disabilities lack access to health care, and if they have any it is merely the same health care program given to poor people in general. The recognition of disability as an abnormality, supported by medical analysis and Islam, is *doxa*, and the social model in opposition to this is *heterodoxa*.

The condition is the same for policies on education, where people with disabilities have been regarded as abnormal people based on medical classifications. As mentioned above, most people with disabilities are placed into special schools with special dorms. They have also been segregated based on their disabilities and based on doctor's diagnoses. The government does not provide accessibility for public schools, and thus does not allow the disabled to join regular classes like other people. This is because government officials believe that the disabled are abnormal people, or not common people. Efforts to make equal right for people with disabilities are done by many NGOs and disability movement activists.

In this context, likewise, the medical model of disability as abnormality is dominant, as in Yogyakarta, only 62 schools out of more than 5,000 offer inclusive education. Despite the social movements that advocate the social model, these counter discourses are comparatively weak and disability as abnormality is still a dominant



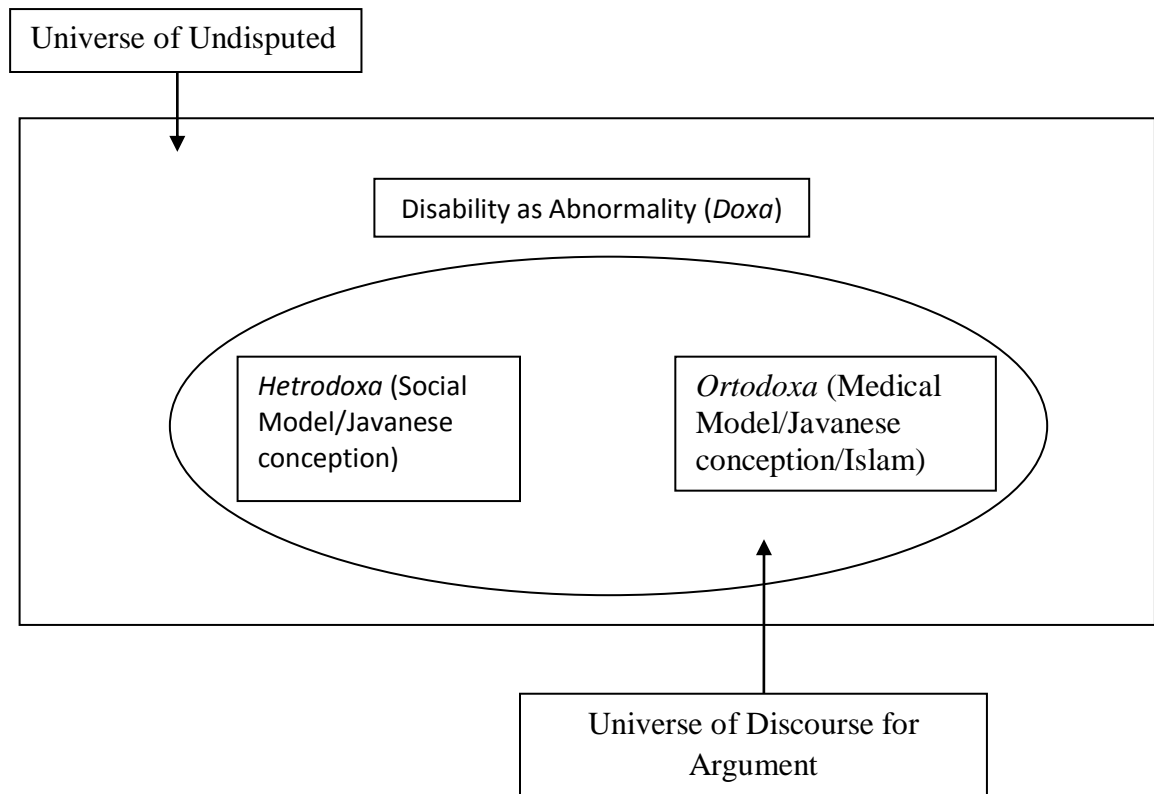
discourse. In these contesting opinions on education and disability, the medical model is the pivotal agent producing the abnormality of disability or *doxa*. Meanwhile, Javanese culture support the idea of *hetrodoxa*, the social model which promote the equality of people with disabilities, so in this context the social model and Javanese concept are on the same side, *hetrodoxa*, whereas the medial model and Islamic concepts of disability support the *doxa*, disability as an abnormality.

People with disabilities, are also not strongly recognized within city planning and design. Almost all public facilities are not accessible for the disabled. This shows how people with disabilities have been forgotten, since they are not common or normal. They are a deviant group, not standing in the majority area.

The above discussion has briefly stated how the “abnormality” of disabled supported by the medical model operates within society and has become *doxa*. The presence of public facilities that are not accessible confirms this premise. Morevoer, the social model is a concept that attempts to give an alternative opposing the dominant belief on disability, so it is *hetrodoxa*.

Like the government policies discussed here, Javanese culture and traditional concepts of disability can also serve as an obstacle for the social model in trying to implement barrier-free environments. Since the Javanese lack a traditional idea of infrastructure for people with disabilities, family-oriented life and communality are factors that clash with the social model. In this case, on the contrary to other policies, the Javanese concept of disability does not support accessible public facilities, and traditional Javanese views support *ortodoxa*.

**Figure 6: The mapping of Contestation of Disability Concepts**



From the discussion, we can see how the contestation of disability happens in Yogyakarta. The positions of people with disabilities who are recognized as special people and people with supernatural powers within society had been altered over time by medical analysis that perceives disability as abnormal. The abnormality of people with disabilities has been reproduced and, due to support by symbolic capital, material capital, and networks, the idea of disability as an abnormality has been absorbed by society throughout Yogyakarta and has become a truth taken for granted. The concept became even stronger when Islam came to Java with the idea of perceiving the disabled as an object of charity. Both concepts are congruent and strengthen one another in perceiving

the abnormality of people with disabilities. Clearly, such abnormality here is a *doxa* that has been produced, supported and perpetuated by medical analysis and the Islamic concept of disability. Due to this, they are *ortodoxa*.

The opposition of the social model to the abnormality of disability, however, has in many cases been congruent with the Javanese concept of disability. In other words, in certain cases, Javanese tradition could also be an *orthodoxa* supporting the *doxa*, though in other cases it could also be a *hetodoxa*. This is the complex portrait of the contestation of concepts of disability in Yogyakarta.

## CHAPTER V

### CONCLUSION

Yogyakarta is a living portrait of traditional cosmology and modern rationality, mixed with religious belief. Throughout the city, elements of Javanese values which actually derived from Hinduism and Buddhism continue to influence the daily lives of people, despite the fact that Islam is the dominant religion. Besides, Yogyakarta is also one of the biggest cities in Indonesia and a center for education with its many big universities.

The condition of Yogyakarta, however, remains a complex situation for people with disabilities. Some of the programs proposed to make equal rights for people with disabilities are quite supportive, but others sometime are not congruent with the people's beliefs related to disability. Shortly, there are various concepts of disability which are contesting each other in Yogyakarta.

Due to this condition, this writing is proposed to explore the concepts of disability that are exist in people's lives and how those concepts give impacts to government policies; health, educational, and public policies. Those conceptions are consisted of Javanese concept perceiving disability as magic, Islamic concept believing disability as an object of charity, medical model looking at disability as an abnormality, and social model conceptualizing disability as a "social construction". Those concepts are contesting each other which could strongly be seen from health and educational policies as well as public facilities. Based on the elaboration, the facts have shown that medical model is the dominant concept.

The first of these is the Javanese conception, perceiving disability as part of their cosmology, whereby people with disabilities are people having magical and/or supernatural powers, keeping the world in balance, thus they should be appreciated and given privileges within everyday life. The Javanese concept believes in disability as a magical thing for people who possess it. This concept has been durably structured within society, and it has been internalized and externalized among people. The concept has been durably absorbed by Javanese people and reproduced and has become a part of the life of the Javanese in Yogyakarta. This process of reproduction appears in various rituals practiced either in the palace or within the society. In the context of Javanese culture, it is difficult to define the actors who produce disability as a special and magical thing, but people in the *kraton* (palace) period and people living in rural areas could be pointed out as the main actors and people who strongly believe in this concept.

The second concept is disability in the Islamic concept, as practiced in Yogyakarta, which tends to believe in disability as an object of charity. This concept has been supported by Islamic doctrines that advocate charity for people with disabilities. This concept then has been internalized and externalized into people's lives and has shaped their treatment of people with disabilities. The main actors in producing this belief are institutions focusing on building special dormitories and special schools for people with disabilities. The religious organizations, such as Nahdlatul Ulama and Muhammadiyah, Muslim philanthropists and, in many cases, the government are connected in a specific network that determines their matrix of perception and treating

people with disabilities. Their perceptions are, then, expressed within the society in which they sit in a dominant position.

The third conception of disability is the medical model of disability, which believes that disability is an abnormality that should be cured. The disabled are in this view a group of deviant people, and they should be rehabilitated and segregated from common or “normal” people. Due to this idea, some governmental policies often separate the disabled from other people. This concept came from Dutch colonialism, and has been strongly supported by colonial power and government. Due to capital, power, and the Indonesian government’s support, this conception has become a dominant discourse for people in general when perceiving disability. The actors for this process are the people in the medical professions, the government or Dinsos (particularly the Department of Social Welfare), and rehabilitation centers such as YAKKUM and YAP Eye Hospital.

The fourth conception is disability from the social model, perceiving disability as a social construction as adopted by the disability movement, NGOs, organizations of disabled people, and so forth. This conception asserts that disability is a social contraction; being disabled is due to social oppression and one’s environment. Moreover, society is actually the cause why people become disabled. Based on this, the deconstruction of the label for people with disabilities and promotion of a new label is the agenda of these activists. In practice, they promote the new term to refer to differently-abled-people, difabled or in Indonesian *difabel*.

The people in these NGOs, organizations of disabled, and people in the disability movement in general are the main actors for the production of this conception. These groups attempt to make an inclusive society for people with disabilities by struggling to implement equal rights for people with disabilities within society. They struggle to advocate for accessible public services, inclusive education that places people with disabilities together with the non-disabled, and for equal protection of the rights of people with disabilities. They form their networks and share their ideas among themselves which is really determinant their ideas on disability, practices and treatment of people with disabilities.

Yogyakarta is a space for contestation of the meaning of disability. We can see, given the facts reported in this study; that such contestation plays out in government policies on disabilities. In this thesis, I have shown this contestation in three types of government policies relating to people with disabilities: health security, education, and public facilities. Each of these policies shows a different example of how contestation occurs.

In health care, the government recognizes people with disability as “abnormal” people, and many policies on health care do not recognize people with disabilities at all. Most government health care programs and policies in Yogyakarta do not recognize people with disabilities as part of their stakeholders. This situation has elicited protests by disability movement activists who believe that disability is a product of social construction and social oppression. In this context, the social model is supported by Javanese culture and beliefs, recognizing disability as an extraordinary phenomenon. The

concept of disability as an abnormality has been produced and supported by the medical model, which is dominant to government policies on health care. Thus, disability as an abnormality is a dominant concept that is supported and produced by the medical model, and the social model and Javanese beliefs are counter discourse for them.

The situation is the same in educational policies, where people with disabilities are still regarded as abnormal people, segregated into special schools based on their type of disabilities and medical diagnoses. Most people with disabilities are placed in special schools with special dorms, and other educational institutions generally require a letter for admission issued by a physician, confirming that one has “normal” physical and mental health. This has been responded to by groups that promote the social model in seeing disability by advocating for the inclusive education for people with disabilities, empowerment, and so forth. In this context, Javanese culture likewise stands with the social model as a concept criticizing the dominant medical model and the concept of abnormality of the disabled, while Islam is part of the a discourse supporting the medical model.

With regard to urban planning and public facilities, the situation is similar, as people with disabilities have been forgotten, since they are not common or normal, and thus they are not recognized in policies on public facilities. In fact, almost all public facilities are not accessible, confirming this premise. However, the social model offers an alternative view, opposing the dominant belief on disability. Javanese cultures, differently in this context than in the other two, conflicts with the idea of the social model in trying to implement barrier-free environments for the disabled, as Javanese culture



believes that people with disabilities are special and have magical power. In this case, Javanese culture is part of the element supporting the dominant concept.

Based on this exploration of views of disability in Java, we can conclude that there are conceptions of disability that take the Western perspective of disabled as abnormal. The Javanese concept of disability, however, perceives people with disabilities as magical and extraordinary people, which is congruent with neither the Western medical model nor the contemporary social model of independent living. The social construction of disability described in Western society—the social model—which argues that people with disabilities are oppressed is not completely true, since not all social constructions, at least in the case of Javanese culture, are oppressive. Within society, as shown in this study, there is actually no single concept of disability, and rather society is a space where many conceptions of disability contest with each other.

The protection of rights for people with disabilities as practiced in many advocacy programs, such as promoting barrier-free environments, should recognize such cultural factors and local wisdom which, in this context, is a type of social capital or that could be used to further such protection of rights. By using this collective social capital, there could be less of a disconnection between Western ideas of human rights for people with disabilities and Javanese traditional culture.

There are several lines of research that would be interesting and important as extensions of this study, including further explorations of disability and social movements in Yogyakarta, including the types of organization of people with disabilities, the way in which they produce their identities, the specific processes by which they

change people's perspectives on disability, and the ways in which they try to change government policies. Other topics for further research include disability and woman, disability and education, disability and economics, as well as disability and natural disasters.

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## APENDIX A: THE MAP OF INDONESIA



Source: <http://www.fbmi.org/images/countrysmaps/ID.gif> Retrieved on October 13, 2011

## APENDIX B: THE MAP OF JAVA



Source: [http://indahnesia.com/indonesia/JAW/jawa\\_information.php](http://indahnesia.com/indonesia/JAW/jawa_information.php) retrieved on October 13, 2011

## APENDIX C: THE MAP OF YOGYAKARTA



Source: [http://www.joglosemar.co.id/yogya\\_map.html](http://www.joglosemar.co.id/yogya_map.html)) retrieved on October 13, 2011