WHEN THE PERSONAL BECOMES POLITICAL:
INFRASTRUCTURAL VIOLENCE AND SOCIO-SPATIAL EXCLUSION OF
PERSONS WITH PHYSICAL DIFFABILITIES IN YOGYAKARTA, INDONESIA

by

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When the Personal Becomes Political: Infrastructural Violence and Socio-Spatial Exclusion of Persons with Physical Diffabilities in Yogyakarta, Indonesia

A Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at George Mason University

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DEDICATION

I dedicate my thesis to the individuals who took the interest in my research and chose to become a part of it. It was my utmost pleasure and privilege to spend nearly five weeks together.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS

Conflict Analysis and Resolution…………..……………………………………CAR
Convention on the Rights of Persons with Disabilitie………………………..........CRPD
Gadjah Mada University…………………………………………………………UGM
George Mason University………………………………………………………..GMU
International Classification of Impairment Disability and Health…………………...ICIDH
Jaminan Kesehatan Nasional ……………………………………………………JKN
Japan International Cooperation Agency……………………………………........JICA
Sanata Dharma University………………………………………………………..USD
Sasana Integrasi dan Advocacy Difabel……………..………………………….SIGAB
Union of the Physically Impaired Against Segregation……………………………...UPIAS
Volunteers in Asia…………………………………………………………………VIA
World Health Organization……………………………………………...........WHO
Yogyakarta…………………………………………………………………Jogja

ABSTRACT

WHEN THE PERSONAL BECOMES POLITICAL: INFRASTRUCTURAL VIOLENCE AND SOCIO-SPATIONAL EXCLUSION OF PERSONS WITH PHYSICAL DIFFABILITIES IN YOGYAKARTA, INDONESIA

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This thesis examines the experiences of people with physical disabilities as they experience inaccessible public and social spaces in Yogyakarta, Indonesia. This paper seeks to contribute to the growing body of literature in the field of disability anthropology by analyzing the notion of "embodied spaces" by pulling insights from multiple fields, such as narrative, urban geography and disability studies on socio-spatial exclusion. Throughout the paper, I analyze how cultural meanings of bodily difference contribute to and perpetuate socio-spatial exclusion for people with physical diff-abilities in Yogyakarta. Through ethnographic analysis, semi-structured interviews and a survey of inaccessible public transportation, public spaces, and community awareness of diff-abilities, I argue that people with physical diff-abilities in Yogyakarta continue to face instances of socio-spatial exclusion stemming from the Dutch colonization from 1602 to 1949 when the Dutch brought with them the medical model of disability. I also explore how people with physical

diff-abilities in Yogyakarta are experiencing new forms of socio-spatial exclusion through globalization and political activism as they demand a more inclusive society.

Keywords: Diffability, disability, space, embodiment, geography, Yogyakarta, Indonesia

CHAPTER 1: DISABILITY AND VIOLENCE

"What we should be asked is not how much it will cost
to make a society completely accessible to all with
physical difficulty, but rather why a society has been
created and perpetuated which has excluded so many
of its members" (Zola, 1982, p. 244)

As of today, people with diffabilities[1] continue to be one of the most marginalized

populations in the world (WHO, 2013). Individuals with diffabilities frequently have

fewer education opportunities, lower economic participation, poorer health, and higher

poverty rates than people without diff-abilities. With an ever-increasing global population

of people becoming diff-abled each year, the World Health Organization (WHO) now

considers the marginalization of people with diffabilities to be a human rights issue

(WHO, 2013). Though, much research on people with diffabilities has been conducted in

the past few decades, much of the literature focuses on policy reforms while maintaining

a distance from people's lived experiences with socio-spatial inequality and

marginalization outside of the Disability Studies field.

Therefore, this thesis seeks to contribute to the growing body of literature in the

field of disability anthropology by analyzing the notion of *embodied space* by pulling

insights from multiple fields, such as narrative, urban geography and disability studies on

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[1] The term 'diffability,' or 'diff-abled' is used in Indonesia to refer to a person with a disability. However, the Indonesian people believe the word diffability or diff-abled holds more humanity in it as it suggests that the person is capable, but engages with life a little differently. Since it holds less of a negative stereotype, it will be the word used throughout this paper when referring to people with diff-abilities.

socio-spatial exclusion. "Embodied space is the location where human experience and consciousness takes on material and spatial form" (Low, 2003, p. 10). This space that is occupied by a person's body and that person's assessment of that space changes as that person's emotions and state of mind, sense of self, social relations, and cultural predispositions grow (Low, 2003).

Therefore, understanding embodied spaces is important to understanding the lived experiences of people with diffabilities because it highlights not just the physical barriers people with diffabilities face, but also the social stigmas that reproduce and perpetuate the spatial isolation of people who are differently bodied. In other words, embodied space provides us with a lens to see how the body is not solely a center of experience, but rather a field of expression (Thornquist, 2006) where the body has desires that can unsettle the order of society (MacPhee, 2003). For people with diffabilities, this bodily desire is often need for accessible social and physical environments and the means of satisfying this need is done through participation in social and political activism. As a result, the order of society previously recognized by those without diffabilities is disrupted. Therefore, embodiment can be seen as more than just the physical body, but also a social body. Though scholars, (see, for example, Low, 2003, 2011; Farman, 2015; Baydar, 2015; Delafield-Butt and Adie, 2016) have written about embodied space, "little attention has been paid to disability as a specific form of bodily difference" (Rattray, 2013, p. 26; Low, 2003) in the field of anthropology in its relation to how people with diffabilities engage with, understand, and create both built and social space (Rattray, 2013, p. 26; Low, 2003). Low (2003) and Low and Lawrence-Zúñiga (2003), argue that anthropology often

neglects spatial analysis as it relates to diffability as a specific form of bodily difference because there is an inherent challenge in defining the body, embodied space, and the cultural explanations of bodily experience, but also because of the "difficulties in resolving the dualism of the subjective and objective body and distinctions between the material and representational aspects of body space" (Low, 2003, p. 10).

This challenge in defining the body, embodied space, and cultural explanations in bodily experiences comes from the need for many researchers to have grounded theoretical formulations that can be rigorously tested through experimentation in a lab where a control and experimental group can be compared against each other and the findings then be generalized to a given society through empirical data collected by the researcher. However, the body, embodied space, and bodily experiences of space and place are subjective in nature and rely on qualitative analysis which is endlessly creative and interpretive. This leaves the researcher without the same type of empirical data found with quantitative research, making it harder for the researcher to prove their findings.

This does not mean though, that qualitative analysis lacks empirical data, but rather that researchers draw on their own interpretive skills to understand and how people make meaning of their lives in bodies and space. As a result of the subjective nature of this work, validity and reliability become a major hurdle as researchers begin to challenge each other and offer their own definitions and research findings of the body, embodied space, and cultural explanations in bodily experiences. Due to this challenge, many anthropologists rely on and build off previously accepted theories of body and space in the field (see for example, Foucault, 1975, 1984, 1986; Bourdieu 1977; Giddens, 1984;

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Ram and Houston, 2015) that create experience-near findings that have proven can be generalized to the larger, social and cultural process of a given society (Low, 2003, p. 10).

Building off the respected work of the scholars listed above, this thesis is designed to address the concerns by many researches that little attention is being paid to diffabilities being seen as specific forms of bodily differences and how those differences then influence other social aspects in a given society through the use of embodied experiences. In doing so, I explore how cultural meanings of bodily differences are used to shape spatial forms of exclusion as this is important to understanding how bodily differences a fundamental role in the creation of stigmas and shame that are unique to individual cultures. Through this exploration of cultural meanings of bodily differences and how they are linked to the creation of stigmas and shame, lead me to question whether or not socio-spatial forms of exclusion then serve as a basis for both individual and collective struggles for survival, spatial justice and dignity?

The exclusion of personal experiences with socio-spatial inequality and marginalization in academia and policy-making is arguably why the past few years have seen a significant increase in people with diffabilities speaking up and demanding that their voices and experiences be heard, recognized, and included in research and policy making meetings. Personal narratives become a vital component in not only understanding the experiences people with diff-abilities have as they are engaging with their surroundings (Mattingly, 1994; Antelius, 2007) but also how their identity is then shaped by these experiences. With this knowledge and understanding, we as a society can

create a more holistic approach when working towards improving the lives of those living with diffabilities.

Narrative research is no stranger to those experiencing some form of marginalization and I want to point out the importance of non-verbal narrative when it comes to working with and understanding people with physical diffabilities and their experiences with their built environment. The term "non-verbal narrative" expresses how people with physical diff-abilities often have to live through their narrative; they perform it, as they physically interact with both the physical and social world around them.

Non-verbal narratives can be expressed as a unique form of art where people make use of physically and spatially telling a story (Dennis, 2002). For example, when a person physically moves away from a person with a diffability, much is being said without speaking a word, or the way people with diffabilities have to engage with their physical environment differently, such as refraining from eating or drinking in public due to the lack of accessible public toilets, tells a silent story of marginalization and inequality. In the words of Judith Butler, "bodies matter" (278) and nowhere is that more profoundly true than when working with people who live with a diff-ability. Understanding the significance of the non-verbal narratives used by individuals with diff-abilities is vital to comprehending their story entirely. Though there is a body of scholars who have dedicated their studies to performative narratives (e.g. Mattingly, 1994; 1998; Langellier, 2001; Peterson and Langellier, 2006), it is not often done so with people who live with diff-abilities.

Furthermore, it is important to note that all narrations, whether individual, cultural, verbal, or non-verbal, they exist in a realm of power (Anteliys, 2009, p. 361). This power can be seen in different dimensions, such as the preference for many researchers to only utilize spoken language. Often, stories and/or narratives are valued as being verbally communicated with a distinct past, present, and future (Nguyen, Heeler, & Taran, 2007). The uses of non-verbal or non-oral narratives not only does not come with distinct past and future contexts as it is only seen in the moment, which requires a certain level of interpretation on the part of the researcher which is difficult, as validity comes into question. Furthermore, non-verbal or non-oral narratives require different methodological approaches and with little research conducted in this area of study, researchers often prefer to stick to the oral approach.

As the number of people with diffabilities continue to grow, researchers recognizing the need to reevaluate the inclusion of narratives, both oral and silent, how we define the body, and how language is the use of power within research concerning the diffability community. One such area of research in the field of disability studies and anthropology that has relatively recently began to take off is in the area of accessibility and public space and how these things interrelate and affect the lives of both people with diffabilities and those living and moving around them that create feelings of spatial exclusion of those who are differently bodied. A prime example of how these different, and yet seemingly normal day to day engagements with life affect people with diffabilities is can be found in Yogyakarta (Jogja), Indonesia where the diffability grassroots movement has recently become increasingly powerful.

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Accessibility and Public Space in Indonesia

The need for people with physical diff-abilities to have free and independent access to public spaces is nothing short of a basic need and yet, is arguably still one of the most significant and challenges many still face. Though accessibility to public spaces continues to be a worldwide problem for people with physical diff-abilities, Titchkosky (2008) indicates that the struggles they face are still in need of more analysis. The reason Titchkosky and other scholars (see, for example, Rattray, 2013) express the need for more analysis in the area of accessibility is because "inaccessible spaces often create a series of uncomfortable choices for people with mobility impairments" (Rattray, 2013, p. 34). For many, attempting to engage with and explore an inaccessible public space means putting themselves in "potentially degrading, humiliating, unsafe, or physically demanding circumstances, which force [them] to depend on others" (Rattray, 2013, p. 34).

As more and more people with physical diff-abilities are beginning to venture into public spheres, it is becoming more evident how built environments have been, and continue to be, designed for able-bodied people. In doing so, the design of the built environment for able-bodied users continue to perpetuate the stigmas associated with people who have a diffability, which ultimately contributes to a lesser quality of life. A prime example of an environment designed for able bodied uses is found in Indonesia where according to a recent report conducted by Japan International Cooperation agency Indonesia, most public places and transportation remain inaccessible while accessibility

laws remain unenforced despite its recent higher level of political stability and economic growth.

The rapid economic growth in Indonesia, however, has brought with it a larger income disparity for the people of Indonesia, which threatens the country's long-term stability. With nearly 15% of Indonesia's population being comprised of people with diffabilities (WHO, 2011; Japan International Cooperation Agency, 2015) and the country's rich history in its conception and treatment of people with diffabilities, Indonesia makes for a great place of study in understanding infrastructural violence and socio-spatial exclusion of people with diffabilities. Furthermore, Indonesia recently ratified the Convention on the Rights of Persons with Disabilities (CRPD) in November 2011 in hopes of securing the rights and freedoms they believe all persons should have.

This study focuses specifically on the region of Yogyakarta (Jogja) "it is one of the strongest provinces in Indonesia in terms of disability awareness" (Thohari, 2013, p. 37) and has "remained at the forefront of those pushing for a new concept of disability" (Thohari, 2013, p. 44) since the 1990's. This prominence in the diffability awareness movement makes Jogja makes this a diverse and knowledgeable area in Indonesia to gather information about diffability related issues occurring in the country.

CHAPTER 2: IMPORTANCE OF LANGUAGE AND SELF PRESENTAITON

The history of diffability in Indonesia has a long and extensive history, something I go into great detail on in chapter three. I find it important to include a chapter in the beginning of this thesis discussing the emergence of the term "diffability" when talking about people living with 'disabilities' as it is a term that remains dominant throughout this work out of respect for the Javanese people whom worked with me as throughout this written work, I strive to highlight the abilities of each individual. Though I stand firm in my decision to use these new terms throughout my work, I cannot help but feel hesitant as these terms were created by and belong to the Javanese people. I strive to give credit throughout this chapter to those who have created the term and work daily to have it accepted as the appropriate term or label used to recognize people with diffabilities on a national level.

The use of language to describe people with diffabilities in Indonesia was a conversation that developed organically over lunch at a local Pizza Hut in Jogja where I had gone out to lunch with one of the women who had agreed to work with me. Alimenia, like most of those working with me used a wheelchair as her primary means of mobility for most of her life. However, unlike most of the others working with me who lost their ability to walk as adults, Alimenia's use of a wheelchair as her primary means of movement came about after a case of polio as a toddler in her home village before the polio vaccine was readily available and families like Alimenia's could access it. Our trip

to the local Pizza Hut came about after I had been in Indonesia for a few weeks and was craving something familiar. Like most places in Jogja, entering into the Pizza Hut required help from both the employees of the restaurant as well as the taxi driver as every entrance involved a flight of stairs, something Alimenia is familiar with. Once inside and seated, which involved ascending yet another flight of stairs, Alimenia and I began talking about the stigmatizing language placed onto people living with diffabilities. It is hard to remember what prompted this exact conversation, as it came about naturally, but once involved, I quickly realized the impact that the local terminology had on people with diffabilities, which encouraged me to further explore the idea of how language is power.

Currently, there is a whole body of literature examining how 'language is power' (Bidder, 1996; Corker, 1999; Valentine, 2002) and how language has the power to change the lives of those who diffabilities for better or worse (Bidder, 1996). Moghaddam and Harré (2010) further argue that language and the use of words are used by people to locate themselves and 'others' in a given place and time. The use of language and how it relates to the difabled community reflects how a given society either includes or excludes and respects or disrespects people with diffabilities (Suharto, Kuipers, and Dorsett, 2016). It is equally likely that the use of negative terminology towards a given group, in this case people with diffabilities in Indonesia, is driven by the lack of knowledge or understanding about diffabilities, why they occur, and the people living with them (Brocco, 2015). The best way to start combatting the negative stigmas people with diffabilities face is to redefine the language used to refer to them, however, it

is imperative that the new terminology comes from the voices of the grassroots, as in those being labeled (Corbett, 1996, Rao, 2001).

The need to redefine the language surrounding people with diffabilities in Indonesia really began to take hold in the mid 1990's in Jogja and Solo regions (Central Java) (Suharto, Kuipers, and Dorsett, 2016) where, according to Alimenia the current local terminology used to describe a person with a diffability is *kelainan* (abnormal), *tuna* (deficit/loss), and *cacat* (defect, crippled, or invalid) (Alimenia, personal communication, June 2016). These terms, according to many diffability activists are seen as perpetuating the marginalization and stigmatization Javanese people with diffabilities as the dominant group (those without diffabilities) have decided they have the power to label and or define those with diffabilities based on their perceived weakness rather than their potential. According to Suharto (2010, 2011a, 2011b), the dominant group, in their defining of people with diffabilities, often neglect to see the social and cultural environments that people with diffabilities face that feed into their inability to fully participate in their given society.

The Creation of a More Inclusive Term

To combat the negative terminologies used to describe people with diffabilities in Indonesia, the grassroots movement for diffability rights began searching for a more inclusive term that recognized not only the person's abilities, but also the human at the center of the stigmatization. In doing so, one of the most prominent leaders of the grassroots movement in Indonesia, Mansour Fakih began using the term *difabel* back in 1996, when he really began to push back against the commonly held terms *cata, kelainan*, and even

disability. Fakih pushed to have the term '*diffable*' replace the commonly held terms such as *cata, kelainan*, and disabled, since he feels as though no one is completely disabled. Therefore, the creation and use of the term difabel is seen as a way to encourage social change within Indonesia, as it points to the complexity of and strengths of human beings.

In hopes of national acceptance of the term difabel and diffability, diffability activists looked to larger organizations to help push the term and counter the hegemony of the more popular outdated terms. Among those organizations are the Dria Manunggal Foundation, the Telenta Foundation, the Inter-Aksi Foundation and perhaps the strongest proponent of the term Sasana Integrasi dan Advocacy Difabel (Center for Integration and Advocacy of the Difabeled (SIGAB)). Their role in the movement was to spread the new terms difabel and diffability through seminars and conferences as they engaged people with diffabilities on the grassroots level as well as those in government positions as they saw promoting these terms as a way of promoting the rights of people with diffabilities throughout Indonesia.

However, even with the help of nationally recognized organizations and a strong grassroots movement, the terms difabel and diffability have yet to be adopted as a nationally or locally appropriate terms within Indonesia. In fact, the terms are largely confined to Jogja and Solo as they are where the terms first took hold. Changing strongly engrained beliefs are embedded into a society is very difficult as the "dominant world-view is highly institutionalized and widely internalized" (Fakih, 1995, p. 57). Though the task of incorporating the new terms into both governmental language as well as societal language is difficult, it is important as most people with diffabilities in Jogja and Solo report that the use of the new terms encourages them to feel more confident about their identity and lives as

people with diffabilities as it highlights their abilities, rather than their challenges (Edmonds, 2012; Evans-Love, 2011; Suharto, 2011b).

Presentation of Self

Scholars working in the disability studies field insist that those working with diffability research need to be reflexively conscious of their "own values, priorities and processes of interpretation" (Barton, 2005) that they bring into their work. Likewise, phenomenologists emphasize the need to understand how human existence "always carries forward its past, whether it be by accepting or disclaiming it. We are, as Proust declared, perched on a pyramid of past life, and if we do not see this, it is because we are obsessed by objective thought" (Merleau-Ponty, 2013). I find it necessary to bring light to the past I carry forward and how it has influenced my present investigation in this thesis. Born in Maryland (United States) in 1984 with my own neurological and physical diffability, I was soon adopted by a nice middle-class family regardless of adoption agencies and doctors advising them not to accept me for the risk of diffability was high. Though I grew up knowing and understanding my diffability, I never identified as a diffabled person. I always fought against that label and never really interacted with others living with diffabilities and this held true till I was 32-years-old and I traveled to Indonesia for a study abroad program in Gender & Conflict and Research Methods.

My arrival in Indonesia during the summer of 2016 is what initiated my curiosity in diffability studies and how it intersects with the conflict analysis and resolution (CAR) field. Upon landing in Bali, I found myself becoming hyper aware of the physical barriers

that existed in nearly every public building, sidewalk, and public transportation setting because of my own limitation in navigating these barriers due to a physical diffability. I spent nearly five weeks with scabs on my hands, knees, and feet from tripping and falling, swollen feet from walking difficult pot hole and sideways ridden sidewalks, sitting out on certain group activities because I physically could not take on the 100's of stairs leading to the destination and upon leaving I took home with me scars from these falls as souvenirs. At times my falls and struggles were humorous, other times they were painful, but most of the time they were just plain aggravating. However, through my own lived experiences with a physical diffability in Indonesia, those who traveled with me to join my classes also became hyper aware of the limitations of those living with diffabilities in Indonesia as they were often the ones caring for me and helping me get around as safely as they could.

Exploring diffability related conflict was not my initial intention upon signing up for these two study abroad courses. However, my work with those with physical diffabilities was nothing less than life changing. My experiences with those that worked with me was more than simply exploring spatial inequalities and violence in an urban environment, but that it also included aspects of self-discovery as I was forced to confront and accept my own bodily limitations. Working with and studying the challenges, limitations, and spatial inequalities and violence against people with physical diff-abilities did not, however, occur without any self-reflection or consideration into the possible problems and dilemmas that may arise from my position as a researcher who held the identity of both "insider" and "outsider".

Exploring people's experiences and subjective understandings of what it is like to live with a diffability in Jogja involved developing a relationship that allowed me to make a strong connection with the individuals who chose to work with me. My relationship with these individuals became profoundly personal as they invited to be by their side and witness their daily interactions with their built environment and social places. Though my interest in exploring the lives of people with diffabilities in Jogja arose from my own physical challenges moving around the city, my access to the diffability community originated through the institutional structures of a study abroad program with George Mason University in Arlington, Virginia and Sanata Dharma University in Yogyakarta, Indonesia. My position as a white, American, university educated, woman on a study abroad trip undoubtedly created a power imbalance that I acknowledge influenced my relationships I developed with the people working with me.

Aware of this power relationship my status brought to my interactions and relationships with the people with diffabilities, I engaged in a research practice that strays from the traditional paths of research. Not only did I allow individuals to guide my research topic, I also disclosed my struggles as a person growing up with a physical diffability and how that affected my own identity all the way up until arriving in Indonesia. I allowed space for the individuals working with me to ask me questions about my diffability and what it is like living with one in the United States and how it affected my relationships not only with friends and strangers but with sexual partners as well as being a mom. My hope in this was to make it clear that I was not speaking to them, or

interested in their experiences strictly as a student, but rather as a person with a genuine interest in getting to know them and their lived experiences.

Despite my best efforts to present myself as a human genuinely interested in people's lived experiences, my status as an American who was economically and socially privileged unavoidably created a divide between me and those working with me. Though this divide is necessary to point out and reflect on, I must say that the majority of people I interacted with were excited to talk to me about their experiences with diffability in Jogja. It is possible that this eagerness to talk to me stemmed from the desire to have a listener, one who found their lives and stories to be important. I also believe this desire to speak with me was the result of my American status as having the power to somehow improve their lives through telling me about their lived experiences. The people's willingness to bring me in and open up to me encouraged me to be an active member of their community as I built connections and made mutual friendships. These friendships have proved crucial to my work and how I chose to go about writing this thesis as I attempt to write in a way that keeps the people at the center of my research as the "experts" of diffability in Jogja and me as a mere co-commentator.

My desire throughout my research is to avoid representation of individual voices in a way that takes the meaning out of individual experiences through heavy analysis that overshadows individual stories with an academic explanation of 'why' something occurred and 'how' the person reacted. However, as the researcher/writer, I am aware that my voice becomes dominant throughout my work as it is the one that narrates. Therefore, to minimize the dominance of my voice, I include unedited quotes and field

notes to place the voices of those I worked with in the foreground of this work keeping them as the creators and owners of their imagery, their ways of knowing, the things they create and produce that are found throughout this thesis (Tuhiwai Smith, 2014, p. 1). However, through my efforts to give space for individual experiences to be shared in a holistic manner does not alter the fact that my writing inevitably does represent others.

Drawing insights from Linda Alcoff (1991) and Gayatri Spivak (1988), which focuses on the problem of speaking "for" others, in this case, people with physical diffabilities in Jogja, I attempt to write in a way that does not further disempower or oppress already marginalized voices while simultaneously attempting to stay away from the equally dangerous notion of "giving voice to the voiceless" (Cary, 2004, p. 70). In their work, Alcoff and Spivak draw attention to the relationship between the researcher and the participants and from what position the researcher speaks. To avoid speaking "for" or misspeaking "for" or about those who worked with me, I kept an open dialogue throughout the thesis writing process. I readily provided drafts for those interested in reading it and encouraged their feedback to ensure the authenticity of the experiences and voices as I attempt to use their stories to speak against the everyday oppression in which people with physical diffabilities experiences in their daily lives.

CHAPTER THREE: ANTHROPOLOGICAL APPROACHES

This research was influenced by my personal struggles, as a person with a physical diffability, that I experienced while engaging with the built environment in Jogja. For five weeks, I engaged in anthropological research on infrastructural violence and socio-spatial exclusion of people with physical diffabilities that included 26 people who chose to work with me. Included here in this thesis are six interviews and 20 survey questioners. Interviews and surveys support the overall findings conducted through observational research that studied the staggering amount of inaccessible and nearly dangerous public places for people with diffabilities. The uncountable dangerous and inaccessible places suggest, to me, an overall lack of understanding and/or caring of the challenges, hardships, and needs of individuals with diffabilities residing in Indonesia.

According to many diffability scholars, the perpetuation of inaccessible public places for people with diffabilities often arise from the lack of understanding to the needs of people of people who are differently bodied stems from the infrastructural and structural violence of an inaccessible environment which then reinforces the social exclusion of people who are differently bodied (Terzi, 2004; Winance, 2007; Oliver, 2010; Owens, 2015). To better understand how people living with physical diffabilities experience and address inaccessibility and social exclusion, in Jogja, I engaged in semi-structured interviews and observational research to explore then notions of infrastructural

violence and socio-spatial exclusion and how the people I worked with make sense of their social and physical world.

Phenomenologically grounded anthropology and socio-spatial theory from the field of human geography as a method of analysis in this thesis provided the means to illuminate the complexity of how people make sense of and share their subjective experiences of how they interpret their world. Phenomenology, according to Ram and Houston (2015) "is an investigation of how humans perceive, experience, and comprehend the sociable, materially assembled world that they inherit at infancy and in which they dwell" (p. 1). Furthermore, phenomenology when used in anthropological work, is a theory of "perception and experience that pertains to every man, woman, and child in every society" (Ram and Houston, 2015, p. 1).

Therefore, both phenomenologically grounded methods and socio-spatial theory contribute to an understanding of how place and space is culturally perceived and experienced in a way that maintains certain hierarchies within a given society that dictate who is and is not allowed to use what 'space'. In other words, socio-spatial theory is a way of seeing and understanding 'space' as cultural, as social, and as political, and not just solely material. Through this understanding of 'space,' one is better equipped to create a field of action that resists and disrupts these often-unconscious processes that give rise to the violence and exclusion of people with diffabilities (Scheper-Hughes, 2014).

Engaging in these two methods allowed me to create a space that defied traditional research methods that states the researcher must maintain an objective and

distanced relationship with a participant by allowing myself, the researcher, to build and maintain close relationships with my participants where equal sharing of experiences brought forth lasting friendships. Inspired by phenomenologically grounded methods, I was invited by my participants to immerse myself within the community of physically diffabled people residing in Jogja, Indonesia which allowed me to listen to and explore the stories, experiences, and some of the most salient issues facing the diffabled community (Scheper-Hughes, 2014). I was first introduced to the physically diffabled community one night at a "break the fast" dinner where community members from Jogja working on some form of activism came to speak with myself and fellow colleagues in a relaxed and comfortable environment. Upon arrival to the restaurant after a long hot day of walking around and my pure physical exhaustion; as a result, I met Lestari, a diffabled social worker working in Jogja.

Lestari was the first person I had encountered with a physical diffability since arriving in Indonesia a week prior. I was immediately drawn to her and quickly found a seat next to her as I wanted to be able to talk about what life is like for people with diffabilities here in Jogja, seeing as in a weeks-time I had already managed to sprain both ankles and skin both knees and hands from falling multiple times. Lestari and I engaged in such an in-depth and exciting conversation that after two hours, we had barely eaten our dinner. The conversation ended with Lestari telling me that she would like me to meet some of her physically diffabled friends. The following day Lestari came to my homestay with her friend, Alimenia who was diagnosed with polio at the age of 4 and uses a wheelchair to move around the city. Through general conversation and a few

shared meals, I was able to build trust with both Lestari and Alimenia to the point that they felt comfortable creating a relationship with me that allowed for their personal and intimate stories of diffability, daily routines, and understandings of their struggles to surface and be shared. Through both informal and formal conversations, as well as semi-structured interviews conducted with a few people, the stories that people shared with me make up the majority of my analysis, along with in-depth participant observation and field notes.

As a feminist scholar, I am largely interested in gender related conflicts. Due to my interest in gendered conflicts, I first began my academic journey to Indonesia with an entirely different field of research in mind. It was not until I actually arrived in Indonesia did I realize how important understanding diffability conflict was to me. Once I decided to change my field of research to diffability conflict in Indonesia, I originally sought to explore gendered experiences of diffability such as domestic and sexual violence against women with diffabilities and how diffability influences perceptions and performances of gender. However, in conversing with Lestari and Alimenia, I quickly realized that gender based violence is, without a doubt a factor that intersects with the lives of people who are diffabled, it was not the most salient issue that they felt needed to be addressed.

As a result, my research shifted towards reflecting and better understanding the most troubling issues that were shared with me in conversation, that of an environment that was built in a way that made it nearly impossible for people with diffabilities to move through with ease. This shift in my work comes from my desire present my participants as the experts of their own lives and situations even if it means venturing

down an unintended path and exploring unfamiliar territory. According to numerous anthropologists and decolonizing methodologies, when participants are seen as the experts over their experiences, one creates an "experience near" rather than and "experience distant" understanding, and in this case, of diffability (Tsing, 1996; see also Geertz, 1974; Duneier, 2001; Phillips, 2011; Scheper-Hughes and Bourgois 2012; Breivik, 2013).

In creating an "experience near" understanding of diffability in Jogja, there is a better sense of closeness between the researcher, participants, and readers because the participant is able to "naturally and effortlessly […] define what [s/he] or [him or her] fellows see, feel, think, imagine, and so on, and which [they] would readily understand […] (Geertz, 1974)." In doing so, I believe ethnography and human geography have the ability to reduce the gap and misunderstandings between the average bodied person and people with diffabilities, which are arguably some of "the most marginalized populations in the world" (WHO, 2013). Therefore, my hope in writing this thesis is to challenge current notions and assumptions of what it is to be diffabled and how diffability manifests within a given society as well as elicit compassion and understanding of those who are differently bodied. To do so, I focus on contextualizing my research within the broader social and political context of what it means to be diffabled from a Javanese, Muslim, Medical, and Social conception of diffability and how that manifests into everyday experiences of diffability, which I further explore in chapter three.

Participant Observation

To explore the way in which Javanese people engaged with their social and build environment, I conducted participant observation throughout Jogja, which includes the use of public transportation, and one local village in Jogja. On a more personal level, I spend numerous hours nearly every day observing and documenting Alimenia engagement with her environment as she moved her and her wheelchair through the overcrowded sidewalks of the Malioboro Market, Gadjah Mada University (UGM), public restaurants and malls, museums as well as Trans Jogja (public bus) and the Yogyakarta Railway Station (public train) and her home. Other personal observations were made with Lestari in her home village in Klaten Jawa Tengah, Indonesia where I met with her family for a traditional Javanese meal and observed how she moved around her environments such as her house and public areas of her village as she introduced me to two other people in her village living with a diffability. To create a broader lens through which to understand of how diffability manifests and affects people, I spent time sitting at various Indonesian food pushcarts lining the streets of Malioboro Market watching how people interacted with and around people with diffabilities as they begged for money.

Over the course of four weeks, I spent the majority of my time with my participants, making observations of both individuals with diffabilities I noticed in the city, or observing the built environment as I engaged in group activities around Jogja with my colleagues. My identity of being a person with a physical diffability positioned me as both an "insider" and "outsider" to my work, allowing me to both participate in

and observe others in my research. This position quickly became my way of engaging with the world as I continued to struggle with my new environment and engaged with those working with me on a daily basis (Atkinson & Hammersley, 1994).

Through the use of participant observation, I quickly became closer to those who were choosing to work with me. This closeness allowed me to go out into the city and village in a relaxed manner, which provided me with the ability to take a step back from formal observations and instead observe interactions and listen to passing conversations from the general population about those I was working with as well as we went out to lunch, shopped for my daughter, or toured local attractions for fun. These casual and friendly hangouts allowed for "nondirective conversational listening" (Snow and Anderson, 1987, p. 1343) that was free from the usual restraints of a formal interview. These informal conversations and interactions are included as material in my field observations.

Interviews

Along with weeks of participant observations, I conducted taped and non-taped, in-depth interviews with four female individuals who identify as having a diffability, one couple who have a child with a diffability, a male individual who identified as having a diffability and worked for an organization providing resources and promoting rights for people with diffabilities in Indonesia and 20 random people of both sexes who self-identified as not having a diffability that were found along Malioboro Market and were willing to take my survey on diffabilities. After gaining verbal consent, I either recorded

the interviews on the audio recorder app on my IPad and later transcribed these audio recordings into a word document, or I manually transcribed the interviews in a notebook I always carried with me and then transferred them to a word document. All interviewed people were Indonesian/Javanese, over the age of 18 and varied in age. Interviews lasted anywhere between 10 minutes to one hour and a half; with two of these individuals, I conducted follow-up interviews during a later time lasting anywhere between 1 hour and 2 hours.

Interviews were set up in a semi-structured manner with questions designed to cover numerous topics about experiences with the built environment and socio-spatial exclusion. Questions were designed to fit the interviewee and were not asked in any particular order. This design allowed for spontaneous discussion, as one question would often lead to sparking the recollection of past events that otherwise may not have ever come up and more times than not, this conversational form of interviewing would result in future questions being answered organically. I specifically chose to take a semi-structured approach to my interviews because face-to-face interviews are highly intersubjective process resulting in me being fully involved in the process and not merely an objective researcher on the sidelines but rather a co-creator of meaning. Therefore, by working within a semi-structured process, I was able to help create an environment open to allowing those being interviewed to talk and share what they felt they needed to share without any interruption.

Throughout this work, there were four interviews that were not conducted in English, but rather Javanese. For these interviews, a translator was provided. The

translator was either recruited through Volunteers in Asia (VIA), or Lestari who agreed to help provide translation when needed. Though the translators provided were trusted and fluent in Indonesian and Javanese, there is still a concern that meaning can be lost or not translated exactly through the use of a translator. According to Aranguri, Davidson & Ramirez (2006), often more is being said than is being translated and at times interpreters change the meaning behind what the participant is saying by omission, revision, and reduction of the content. Furthermore, if the interpreter feels as though the participant is speaking in an informal manner, then that content is often disregarded and not translated to the interviewer.

With this ethical concern in mind, I still found it important to allow people to interact with me in the language they were most comfortable using. A person's language "is a means of identity as much as it is a tool of empowerment and representation" (Jankie, 2011). With Indonesia being a previously colonized nation state, the use of English while working with the Javanese can potentially be problematic as it can disrupt one's identity and system of knowledge as distinctly Javanese. Thus, the English language contributes to the already existing power relations within interactions I have when interacting with the Javanese people working with me.

Therefore, when working with a translator I made a point to asked many clarifying questions to minimize the chances of distorting the meanings behind what they were telling me. In doing so, I believe I was able to lessen the power relations between myself and the people I was working with because I did not privilege one language over another.

CHAPTER 4: THE CULTURE OF JOGJA AND CONCEPTIONS ON DIFFABILITY

To best understand diffabilities and the people living with them in Jogja, one must first have a better understanding of the long-held history, culture, and identity of this province as it is strongly linked to the conception and treatment of Yogya-nese with diffabilities. First founded in 1755, Jogja is one of Indonesia's 33 provinces and is known for being the capital of the Mataram Kingdom during the Dutch colonial era. Jogja is bordered by the Indian Ocean to the south and Central Java Province, such as the Klaten Regency to the northeast, Wonogiri Regency to the southeast, Purworejo Regency to the west and Magelang Regency to the northwest. Historically, Jogja has been the site of many rebellions and social movements, starting with the resistance against the Dutch Colonial rule and economic policies. Today, Jogja is the only province with a traditional kingdom, however, titles have changed to represent a more democratic governance with Sri Paku Alam VIII acts as vice governor, and Sultan Hamengkubuwono X serving as an unelected governor. As of today, Jogja has the strongest diffability grassroots movements of the country. The work in this chapter is largely based off the work of Slamet Thohari, a diffabled man and lecturer at the Department of Sociology and co-founder of the Center for Disability Studies and Services at the University of Brawijaya, Malang Indonesia as published work in this area on diffability in Indonesia is limited.

Geographically, Jogja is the smallest province in Indonesia, only accounting for .17% of Indonesia's total land area (Thohari, 2013). Even though Jogja is known as the largest academic and tourist area (outside of Bali) in Indonesia, the majority of Jogja's population is middle-aged and elderly. With this higher number of middle-aged and older adults living here, Jogja is considered to have one of the longest life expectancies. As of today, despite being the education capital of the country, Jogja's most favorite occupation is still agriculture with wholesale, retail, trade, and grocery following closely behind.

The Culture of Jogja

Thought my interviews and conversations with numerous people throughout Jogja, the way in which culture and religion was narrated and explained was shown to be an important aspect of how they self-identified and identified other's thoughts and behaviors. Though these narrative creations of the culture of Jogja have been contested, politicized, and changed throughout history, as outlined in this chapter, I want to make note that there is no one instance that holds true for every person in Jogja, but rather a way in which to better understand those with whom I worked with and how they have narrated their understanding of their world to me.

For many, it is seen that traditional cultural values, beliefs, and religion are strong and often influence societal norms. Though Islam is the dominant religion in Indonesian, as Indonesia is the largest Muslim country in the world (Central Intelligence Agency, 2010) though not to be mistaken as an Islamic State (Agustian, 2016), it is not limited to this religion alone. Other religions found in Jogja are Catholicism and other Christina

denominations, Hinduism, and Buddhism. For many people, Jogja is a place where

traditional Javanese culture and Islam becomes a way in which many people create and

understand the outside world. Communality and togetherness, for many, are considered a

highly valued belief in Javanese society. In Java, there is even a saying pointing to the

importance of communality which says, "it is not important whether we can eat or not,

but the most important thing is togetherness" (Thohari, 2013). Therefore, at times, if one

deviates from this idea of a strong communal identity and way of being, it can result in

being shunned and considered, unlike Javanese.

    With connection to communal values, many Javanese people are always

conscious of how "people continually [move] in to and out of one another's space"

(Mulder, 1992, p. 4) and therefore never alone in life. This connection with one another is

easily seen throughout the many social settings found in Jogja. It may take the form of a

nod or acknowledgment of another when walking past someone, or through a group of

people as a way of asking permission to pass by someone they may or may not bump

into. Though these are only two examples, exchanges of politeness are considered

obligatory rituals between individuals. According to Mulder (1992), these rituals take

place as a form of mutual acknowledgment and respect for each other's existence as they

share the same social space.

    Mutual respect and acknowledgment of one's existence also extend to the belief

in a hierarchical family and social system. Thought beliefs have shifted over time, it is

still considered by many that village leaders, upper-class people, and the elderly are to

always be treated with respect and not directly criticized. Linguistically, for the elderly,

this respect can be seen in the usage of words used to address them. For example, if one does not know the senior well, it is expected that a younger person speaks with middle-respect. If the older adult is well known, one should speak in a familiar register. According to the anthropologist Geertz (1961), "unlike some usages in the West, respect here does not necessarily refer to an attitude towards a person superior in power," (110) instead, in Javanese culture, respect consists of fear, shame and reluctance (114).

It is important to note that the term "respect" in the Javanese culture is particularly difficult to translate and the ideas of fear, shame, and reluctance being connected to respect can be even more challenging for a Westerner to understand. The Javanese words for respect are *urmat* and *adji* and have complex meanings which barley overlap with the American idea of respect (Geertz, 1961). In Jogia, there are three words in the Javanese language that are often used that denote the three stages of feelings that are used for different situations where respect is expected. These words are *wedi*, *isin*, and *sungkan.* These feelings range from intensity with *wedi* being the most intense feeling to *sungkan* which is the least intense. *Wedi* is best translated as "afraid" or "fear" in both the physical and social sense tied to an unpleasant consequence. For example, it is often taught that all Javanese children should be *wedi* of their elders and if they are not *wedi* of them, they will not obey them (Geertz, 1961). Here, we can see that *wedi* best translated into "fear" is also seen as a form respect through obedience.

Isin, which is the next feeling which is best translated as "shame, shyness, embarrassment, guilt" (Geertz, 1961, p. 111). *Isin* is thought of as the first stage of growing up where when you experience an uncomfortable situation, usually experienced

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with someone above your social status. For example, *isin* is usually experienced when you take something from a friend without them knowing and they later find out and confront you, you feel *isin* or according to an interview conducted by Geertz, a woman told her that "if there is a club and I have a position in the club lower than anyone else, I feel *isin*" (Geertz, 1961, p. 112). Therefore, *isin* can be best described as a complex social anxiety reaction to a social transgression. Lastly, *wedi*, similar to *isin*, is translated as a fear based reaction to treats stemming from social situations but are tied to more physical threats (Geertz, 1961). From a young age children are socialized into when they should feel *wedi* and *isin* and are in fact praised by their parents for being *wedi* to their elders and *isin* to their equals.

Historically, hierarchy extends beyond respectful speech and also includes the duty of parents to care for and nurture their children as they teach them to learn the rules of society, such as Javanese values, and respect for others (Riany, Meredith, and Cuskelly, 2017). According to Hitlin and Piliavin (2004), cultural values dictate what behaviors are acceptable to a given community. Furthermore, Schwartz and Bilsky (1987) explain that these cultural values, concepts, beliefs, and behaviors extend beyond specifically outlined situations. Though these norms have shifted over time, it is still seen by many that parents should be honored and respected as they are seen as the center of "life" (Mulder, 1992). In some areas of Jogja, such as villages, folklore as told through stories and personal narrations to me through interviews with Lesteri and Alimenia, suggest that if children do not respect their parents, they will be cursed (Mulder, 1992) or gain negative Karma (Widayanti et al., 2011). For some, this negative Karma for

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disrespecting parents might be having a child born with a diffability (Riany, Cuskelly, and Meredith, 2016, Lesteri & Alimenia, 2016).

In relation to the importance of family, respect, and family ties, many Javanese still consider themselves belonging to both an extended and nuclear family. Most Javanese have close relationships with their relatives and preserving these relationships is a form of honor. These close relationships and the need to protect them can be seen during the days following the end of Ramadan where millions of people travel and come together, and families reunite in a grand display of togetherness as they ask for forgiveness for any wrong doings they have committed against another in the past year. Furthermore, Javanese parents often take the responsibility of their child's growth very seriously as the parents are the ones judged through their child's performance in society (Geertz, 1961). An example of this comes from the idea that if a child gets into trouble or if they behave and perform well, they are often asked what their parent's names are before they are asked what their name is, if asked at all (Mulder, 1992).

Despite Islam being the dominant religion, Javanese myths, cultures, and rituals have deep roots embedded throughout the city. Some Javanese even have a strong spiritual connection with Merapi, an active volcano and ratu kidul, the queen of the southern oceans (Woodard, 1989). Within this belief, some Javanese feel as though everything in life has a place and is part of God's plan. This plan is then believed to provide a sense of balance, and regulated order and a disruption to this is a cause for concern (Mulder, 1992). As a result, those who live with this belief often consider their behavior in life is part of God's plan, meaning what happens to them, both good and bad,

are happening as they should be. However powerful the people's connection with God is through Islamic cosmology, one cannot help but notice how traditional Javanese mythologies are when interacting with many of the Javanese people.

In fact, historically, the strong belief in the metaphysical for many, though it has changed throughout history as societal norms have shifted, was so strong that the city of Jogja was designed based on these cosmological beliefs in harmony and balance of world and life. Though globalization has brought with it an array of malls, shops, and hotels, one can still find traditional architecture such as a statue of the Sultan's union with God, interwoven into modern Jogja. As Indonesia continues to witness waves of globalization, perspectives of what it means to be "Javanese" for many, have continued to be challenged and continue to shift throughout time.

Most recently, scholars interested in Jogja's diffability community have begun to explore how these shifts in society relate to those living in Jogja with diffabilities. Today, Indonesia is seen as hosting multiple modes of being and belonging that have historically been contested and shifted over time. The four most prominent concepts of diffability include the older metaphysical and cosmological conception, the Islamic (and Islamist) conceptions of diffability, and more globalizing models such as the medical model and social model.

Jogja and People with Diffabilities

Today, Jogja has one of the strongest diffability movements throughout the country regarding awareness, to the need for better inclusion and diffability related social

services, which can be seen through many of its pilot programs aiming to make the city more accessible. Based on a report conducted by Japan International Cooperation Agency (JICA), as of 2015, there were 157,985 people with diffabilities living in Jogja alone (JICA, 2015). It is believed that the number of people with diffabilities increased following the May 27, 2006, earthquake as the loss of life and economic and structural damaged that occurred caused people to flee to Jogja (Elnashai, 2010). With a significant amount of people with diffabilities, the diffability rights movement in Jogja has produced significant results in regard to creating a more inclusive and accessible society regarding legislation. However, according to many of the people I spoke with, the laws that do exist, that are designed to make both infrastructure and social aspects of life more accessible, still lack enforcement which results in little to no changes.

Early Javanese Conception of Diffabilities

As discussed previously, some Javanese people, more than others, rely heavily on myths, cosmological beliefs, and communality, which contribute to the way they see and understand diffabilities. To better understand the connection to mysticism, karma, ghosts, and diffability in this particular belief system, one must have an understanding of wayang (puppet) stories. Wayang is a Javanese religious mythology that is considered by many to be central to the Javanese way of being (Anderson, 2009) as it is often used as a guide that shapes people's view of life and the way things are supposed to be (Sumukti, 1990; Weintraub, 2004; Thohari, 2013). Within the wayang, there lies a special place for people with diffabilities. Within these traditional Javanese stories, one can find numerous deities

with different diffabilities succeeding in life and gaining great respect from the Javanese people.

As a result, the early Javanese understanding in much of society, saw people with diffabilities as possessing magical powers and the gift of prophecy that cannot removed from day-to-day life (Pemberton, 1995). Though different diffabilities were considered to accounted for different types of respect and magic, people with all kinds of diffabilities were generally treated with respect. For this reason, many of the early Javanese people would often consult people with diffabilities about their luck or what their future holds. Also, it was commonplace to find a person with a diffability, specifically a little person, in Javanese castles as kings and sultans often believed they strengthened the Javanese kingdom as well as the power of the king (Anderson, 2009).

Though much of this belief has been traced back to the early times of Javanese culture, for some, this cosmological belief of people with diffabilities being adorned with special powers can be found in present day Jogia among some people. This belief was brought up during one of my many conversations with Alimenia. As we sat staring at the court yard of her old childhood school, Alimenia began a casual conversation about how, as a child, she was given the ability to see one's future as a result of her diffability. However, Alimenia did not consider it to be a good gift, one filled with good fortune. Instead, Alimenia saw it more as a curse as her gift was based primarily on being able to see if the individual was going to die soon. Therefore, Alimenia begged and begged God to take away her gift as she felt a tremendous burden of whether or not to tell someone they were about to die. Shortly after, her ability to see the dark shadowy figure

disappeared and she felt free of that burden (Alimenia, June 2016, personal communication).

Current Conception of Diffability in Javanese Life

Today, in modern Javanese life, much of diffability as magic is largely considered to be a part of Javanese cultural "myths." Instead, many Javanese have shifted their perceptions align diffability more with family and community. With family being an integral part of many people's lives in Jogja, many people believe it is the parent's job to care for their children till the age of njawani (becoming Javanese) (Thohari, 2013), it is also believed that parents and families are to protect people and family members with diffabilities. The typical family social life includes older family members, such as older siblings, care for younger family members, including those with diffabilities. Since family members with diffabilities are seen as attached to the family home, often elders, such as grandparents or even parents view their grandchildren's or children's diffabilities as part of their responsibility.

During two of my visits to two separate family homes in a local village in Jogja, I learned of this very belief. When visiting with one paralyzed elderly woman who is a married mother of two, she talked about how each of her children (one daughter, one son) take turns living in Singapore to work and support the family and living at home in their village to care for her while her husband is in the fields working. The woman had become paralyzed a few years back after falling and breaking her back doing work around the home. As of today, she spends her time laying in one position on her bamboo bed, as

moving around is too painful due to multiple infected bed sores and muscle spasms in her legs. Through a painful tear-filled testimony, the woman discussed the burden she puts on her children by being paralyzed. She talked about how each of her children now have to go spend two years in Singapore working to support the family while the other stays behind to care for her because without her contribution, working in the fields with her husband, and her monthly medical bills, they simply cannot afford to live. Though she felt as though she was a burden to her children, the son who I talked to stated that as her child, it was his job to care for his mother, thus showing this strong Javanese connection and dedication to family.

Another example of this family structure comes from another village family I met with. The couple's son was born with hydrocephalus.[2] As a result, their son is wheelchair bound and completely dependent upon his parents to keep him alive as he has no ability to take care of himself on his own. It was obvious how much this family loved and cared for their son as they talked about his favorite T.V. shows, food, and past times. With my ignorance regarding the Javanese custom of caring for family, I asked the parents of this boy what will happen to him when they pass. Staring at me with a funny look, they both said, "well his siblings will care for him of course." As a Westerner, the idea that your siblings would automatically care for you if you were unable to care for yourself was completely foreign, but goes to show how this idea of family responsibility is taught so early in life, that siblings do not second guess caring for each other.

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[2] Hydrocephalus is a condition where there is water on the brain causing the head to swell (NIH Factsheet, N.D.)

Tying the belief in cosmology and myths to the strong belief in communality, and family in rural areas of Jogja, many people, have a strong belief that diffabilities are the result of bad karma or the doings of a ghost. In a conversation with Lestari (2016), a UCP social worker and paraplegic woman in her home village just outside Jogja city we discussed this very phenomenon. According to Lestari, not too far from here home lives a little boy who was born blind. Both his family, as well as the rest of the village believe his blindness is due to his grandfather's bad karma being passed down through his family and onto him. Years before this boy's birth, his grandfather was caught in the middle of a land conflict. His grandfather was advertising five hectares of land to be sold and once he found a buyer and they paid him for the land, the grandfather argued that he had only sold three hectors of land, thus being suspected of trying to rob the new owner of 2 hectors of land they believed they paid for. Because of this grandfather's doing, the family was cursed, and the grandchild was born blind as a repayment for his grandfather's dishonesty. Though Lestari no longer believes bad karma is the result of this boy's blindness, nor any other diffability for that matter, she argues that in the majority of Jogja's rural village, people continue to believe one's diffability is the result of bad karma (Lestari, 2016, personal interview).

Next, Lestari and I discussed the long head belief in the villages that ghosts wishing to feed off human souls causes many of the fatal or severe car or motorbike accidents, like the one Lestari was involved in years earlier. Her journey into the world of diffabilities began when she was just 23 years old and involved in a motorbike accident that left her paralyzed from the chest down. Lestari was a passenger on the back of a

motorbike when it crashed into a ditch to avoid being hit head on by a truck. For most villagers, they believe accidents such as these are caused by ghosts walking the streets looking to feed. For these spirits to feed off the souls of the people, the people must first die. For this to happen, the ghosts go out into the street and grab the handlebars of a motorbike of an unsuspecting motorist, causing them to crash.

If the person dies, it is considered a successful hunt and the ghosts eats. If the person does not die, it is regarded as an unsuccessful hunt (Lestari, 2016, personal interview). Other times, the ghost may be "owned" by someone or a family. In this case, the "owner" of the ghost will send it into the street to feed and as repayment to its "owner." The ghost will then also rob the person who has died in the accident of their money and bring it to their "owner" (Lestari, 2016, personal interview.) These two stories of why the Javanese people become diffabled and are long held traditions that can still be found throughout rural villages today. The belief by many, but not all, Javanese people that people with diffabilities are the result of some kind of karma is not something that can only be found in aspects of Javanese culture, but also interwoven in religion

Islamic Conception of Diffabilities in Jogja

As mentioned previously, Islam is the dominant religion among the Javanese and often has a significant influence on the way some people conceptualize and understand diffabilities. However, as also mentioned before, Islam in Indonesia is mostly practiced differently than in the Middle East as the belief system incorporates local myths, beliefs, and culture, which also play into how many of the Javanese Muslims view diffabilities.

To have a better understanding of Islam and diffabilities, we need to explore Islamic teachings of diffabilities and the people living with them. Islamic philosophy, in general, is considered to have a positive attitude towards people with diffabilities. However, one can argue that this positive attitude can be regarded as more of a benevolent ableism where people with diffabilities are treated well solely because they are seen as objects of charity that must be taken care of in the eyes of Islam. This concept is touched more in-depth below.

This benevolence can be seen through the Qur'an and the Hadith's[3] teachings that suggest that diffabilities are natural and part of the human existence and go on to provide followers with principles and suggestions for caring for those living with diffabilities as well as how they will be rewarded for such caring (Al-Aoufi, Al-Zyoud, and Shahminan, 2012). For example, in Islam, it is taught that "all people belong to one human family; every person is created out of the same father and mother—implying that this equality of biological origin should be reflected in the quality of the human dignity common to all" (Bazna, and Hatab, 2008, p. 12). Furthermore, the Qur'an suggests that people with diffabilities encounter barriers to their full integration and inclusion in society through societal constructions of diffabilities and therefore, it is societies job to continuously improve these social conditions.

In further support, one can find Hadith narrations that profess the need for one to behave with cooperation, solidarity, compassion, and respect towards all persons,

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[3] The Hadith is a collection of traditions and sayings by the prophet Muhammad that discusses his daily practice and make up the majority of guidance for Muslims apart from the Qur'an.

diffabled or not. One such story of compassion for the diffabled, which is rooted in Islam is that of Omar Ibn Al-Khattab, the third Muslim leader who went out of his way to provide a blind boy with a place to stay near the local mosque after he received complaints about the boy being unable to reach the mosque for prayer (Al-Aoufi, Al-Zyoud, and Shahminan, 2012). Another example comes from the second Islamic state in Damascus when the Umayyad caliph, al Walid ibn Ad al Malik, established a special place to live for people with intellectual diffabilities and their assigned caregivers (Al-Aoufi, Al-Zyoud, and Shahminan, 2012). Though only two examples of how Islam strives to teach followers to view and understand people with diffabilities, they provide Muslims with a guide as to how to assist those "in need."

Within the Indonesian and Javanese context, however, Islamic teachings of people with diffabilities are not always interpreted by some of the Javanese as positive. For example, in Java people with diffabilities are barred from conducting religious rituals or becoming an imam in prayer (Thohari, 2013) and therefore can be understood as belonging to an inferior position within society. The belief that people with diffabilities cannot serve as leaders with in Islam extends beyond the religious context in Java and includes being unfit to serve as leaders, period.

Due to Islamic perspectives, as well as traditional Javanese cosmological perspectives shaping many of the people's views in Jogja, it is considered by some that diffabilities are a way of testing people's lives and religious faith. If one can handle their lot in life, such as dealing with their diffability, they will be provided with unique merits and rewards from God (Thohari, 2013). As a result, many Muslim people do their best to

live their lives under strict Islamic teachings. For example, during one of my many conversations with Lestari, she explained how much it meant to her to be a Muslim, which meant being able to attend Mosque services and pray. In her village, her Mosque is not accessible, so during the services, she must remain outside to pray alone. Only during large celebrations do her friends and family carry her into the Mosque for prayer (Lestari, 2016).

Furthermore, general Islamic belief in Java sometimes views people with diffabilities as objects of charity. Though as described above, it is argued that Islam preaches acceptance and compassion for those with diffabilities, it is said that some Javanese people interpret the Islamic teachings to mean people with diffabilities are to be cared for because they are weak and unable to care for themselves. This act of caring is often seen as coming from a place of benevolent ableism. As most Javanese Muslims believe that as Muslims they must provide care for those "less fortunate" and with "bodily difference," but not out of the idea that they are inept and weak. However, many argue this perception of Islamic teachings in Java is dichotomous to their actual meaning. Asad, an Austrian Jewish scholar who to Islam, (1999) argues that "as long as we have to do with human, biologically limited beings, we cannot possibly consider the idea of 'absolute' perfection, because everything absolute belongs to the realm of Divine attributes alone" (p. 10).

Medical Model of Diffability

Bodily differences have been present from the dawn of time with every culture and every person viewing and understanding them differently. Numerous academic fields continue to hold unique views of bodily differences, which are often in opposition to each other. The term disability[4] for example, has historically been situated in the Western context of biomedicine, which is outlined in the Medical Model of Disability. In principle, the medical model argues that the problems faced by people with a disability are seen as an issue belonging to the individual, not society. Therefore, under the biomedical model, disability is seen as an illness caused by a sequence of events that leads to a type of pathology, which is made visible through physical symptoms (Whyte and Ingstad, 1995). With the display of symptoms, the illness is then identified, and a cure is then sought (Winance, 2007). As a result, people with disabilities are encouraged to visit an expert authority, such as a medical doctor, who can treat the person's physical symptoms "objectively" so they can be perceived as a "normal" person to the rest of society (Parsons, 1951).

The medical model and 'the sick role' has been widely accepted by numerous countries, organizations, and in academia as a way to define disability. Pulling from the medical model and the International Classification of Impairment Disability and Health (ICIDH), the World Health Organization (WHO) defines disability as a "problem in body function or structure; an activity limitation is a difficulty encountered by an individual in

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[4] The term 'disability' is used here as a reference guide as disability is a universal and medically known term.

executing a task or action" (WHO, 2016, para 1). Those in support of the ICIDH state that this classification system is "useful in numerous fields such as social security, health care, welfare, health statistics and social service delivery" (Thohari, 2013, p. 5). When one is classified as disabled under this definition, disability then becomes a pathology of function that "substantially limits one or more major life activities" (Americans with Disabilities Act, 2009, para 3), which includes but is not limited to difficult in performing manual tasks, seeing, walking, hearing, speaking, learning, breathing, and working (Hood College, N.D.). Once categorized as "disabled" under the medical model of disability, one is then sent for rehabilitation to "treat" one or more of the diffabilities listed above.

The medical model of disability was first introduced to Indonesia through the Dutch colonialization (1602-1949) when the Dutch brought Western doctors to Indonesia for their own medical needs. As a direct result, in 1626, Indonesia saw its first Western hospital that was built to study and treat tropical diseases at afflicted the Dutch people (Boomguaard, 1993, Triratnawati, 2016). I find it important to note that this hospital, along with future Western hospitals restricted Indonesian people from being treated here unless they were given special permission, as Western medical treatment was seen as a military affair (Sciortino, 1996). Alongside Dutch colonizers were the Catholic missionaries who were also introducing and pushing the Western model of disability onto the people of Indonesia through their nursing services (Thohari, 2013).

Under the governorship of HW Daendels (1762-1818), a Dutch general, hospitals for treating military personnel began popping up rapidly throughout Indonesia. As hospitals began to spread to the more rural areas of Indonesia, specifically Java, the

Javanese began to shift their traditional perspectives of medicine and diffabilities to a more Western perspective on medical treatment (Scoute, 1937). As a result of this shift in perceptions, people with diffabilities went from being highly respected and regarded as possessing supernatural powers to people who were pathologically afflicted and needed to be cured through Western medicine. For the most part, Dutch hospitals did not actually treat Indonesian people, but rather carried out research projects on the Indonesian people through the introduction of eugenics, which influenced the discrimination against people with diffabilities (Pols, 2010). These eugenics projects were the basis for establishing mental hospitals for those deemed mentally ill or abnormal. Through the establishment of mental hospitals, Dutch doctors and psychologists pushed further for the exclusion of those with diffabilities by establishing schools for children with diffabilities, which can still be found and are widely used today.

The idea that people with diffabilities are afflicted with a biological pathology causing them to become diffabled and in need of treatment lead Michael Oliver (1990) to develop the 'personal tragedy theory.' Here, Oliver states that the medical model is founded on the idea that people with disabilities suffer from one or more impairments due to some tragic circumstance which limits their ability to perform certain tasks that "non-disabled" people can undertake easily. As a result, people with diffabilities are often forced to take on what is called 'the sick role' (Haber and Smith, 1971), which suggests that illness or disease are the driving forces behind a disability (Barnes, 1990; Oliver, 1990). According to Parsons (1951), diffability, as it relates to sickness, is then seen as a form of social deviance that challenges societies equilibrium.

In the search for maintaining societal equilibrium by "curing" or "treating" people with diffabilities, a doctor by the name of Suharso became a driving force for medical rehabilitation in Indonesia, specifically the Jogja and Solo regions around 1940. During the fight for Indonesian independence, Suharso treated wounded or newly diffabled Indonesian soldiers near the front. In the year 1946, Suharso established a rehabilitation center focusing on the treatment and rehabilitation of people with diffabilities (Thohari, 2013). Part of this rehabilitation center included a prosthetics center for soldiers who had lost limbs in the war for independence. In coming years, Suharso's rehabilitation center became the largest in all of Indonesia and now serves as a model of rehabilitation for centers in Jogja.

Though Suharso arguable improved the lives of many, his view of people with diffabilities being in need of rehabilitation had a strong influence on the Indonesian government, which quickly began to see people with diffabilities as a type of social pathology within (Thohari, 2013). As a direct result, the issue of diffabilities was reassigned from the Ministry of Health to the Department of Social Affairs. In Indonesia, the Department of Social Affairs addresses issues pertaining to displays of, what they define as social pathologies such as prostitution, transgendered people, beggars etc.,[5] (Thohari, 2013).

Due to Suharso's work and the more recent development of the rehabilitation center, hospital, and medical science of one of the largest and oldest universities in

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[5] This thesis, nor I the author, does not lay claim or necessarily agree with the definition of social pathology as it is laid out under Indonesian belief.

Indonesia, Gadjah Mada University with the support of Dinsos (Department of Social Affairs), the perpetuation of the medical model of disability remains the strongest model and conception pertaining to people with diffabilities in Indonesia today. As Jogja continues to be seen as standing at the forefront of medical advancements in Indonesia today, many people from the diffability community have come together to push back against this model and the idea that diffabilities are caused by the medical manifestation of a biological pathology belonging to an individual person and are advocating for a more inclusive model, such as the use of the social model of disabilities. This social model is something many Javanese people with diffabilities consider important to their lives as it focuses on people with diffabilities humanness, strengths, and needs while placing the pathology of diffability onto society's inability to make their social and physical environment accessible in a way that allows people with diffabilities to meet their full potential in life.

The Conceptualization of the Social Model of Disabilities in Jogja

During the early 1970's the world saw a shift in the way it viewed diffabilities. This shift was seen at a time when much of the West was engaged in anti-segregation movements, mostly targeting racial segregation. However, underneath these racial anti-segregation movements a resistance movement against the segregation of people with diffabilities from society was brewing. Much of this resistance movement was driven by Paul Hunt and his organization, the Union of the Physically Impaired Against Segregation (UPIAS) 1972 (Beckett and Campbell, 2015). The social model of disability

grew from this movement and quickly became a way for disability activists to "identify

its injuries and to articulate its grievances" (Hoy, 2005, p. 6) against the medical model.

In direct opposition to the medical model, the social model's founding principle that a

person's disability is not the cause of their social exclusion or restricted movement, but

rather these issues are a result of an inaccessible environment and therefore, the 'cure'

lies squarely with society (Terzi, 2004; Winance, 2007; Oliver, 2009; Owens, 2015).

To date, the social model of disability has "demonstrated success for disabled

people in society, challenging discrimination and marginalization, linking civil rights and

political activism and enabling disabled people to claim their rightful place in society"

(Ownes, 2015, p. 385). The UPIAS released a statement back in 1976 which stated:

> 'Disability is something imposed on top of our impairments, by the way we are
>
> unnecessarily isolated and excluded from full participation in society. Disabled
>
> people are therefore an oppressed group in society" (UPIAS, 1976, para 4).

In support of UPIAS's understanding of disability, Oliver (2009) argues people with diff-

abilities have historically been oppressed by an uncaring and ignorant society, which is

the cause of disability. Proponents of the social model argue that its very creation has

provided people with disabilities the room to challenge this socio-historic oppression

through political activism (Finklestein, 1990; Oliver 1990). Furthermore, this political

activism quickly became a driving force that has created the social and political change

we see today (Longmore, 2003; Oliver and Barnes, 1998).

The social model of disability was first introduced to Indonesia through Mansour Fakih, an Indonesian man who engaged in a study abroad program for both his master's and Ph.D. at the University of Massachusetts in the United States. Mansour was a social justice pioneer in Indonesia and established numerous NGOs, and in 1997, he was named the head of Oxfam in Indonesia, which helped to connect multiple NGOs making the social justice movement in Indonesia stronger. Here, he began to focus on the segregation of people with diffabilities throughout Indonesia. Joining Mansour's mission was Setyadi Purwanta, a blind man involved in diffability activism. Before becoming blind, Purwanta was an activist in an NGO involved in promoting human rights and democracy. Together, Mansour and Purwanta concluded that the belief that people with diffabilities were "abnormal" led to their segregation and discrimination.

One NGO in particular, Dria Manunggal, quickly became one of the most outspoken and strongest organizations in Indonesia to work towards deconstructing the current social construction of diffabilities as being 'abnormal.' This NGO is made up of mostly interns with a few core staff members. From here, many of the interns go on to create their own NGO's designed to support people with diffabilities and work towards a more inclusive society. In an attempt to create this more inclusive society, Dria Manunggal and other local NGOs host what is called "Sunday morning gatherings," in downtown Jogja where they discuss the rights of the diffabled and the biggest challenges facing people with diffabilities that prevent them from being included in society (Thohari, 2013). During these public meetings, people throughout the society are invited to join the conversation; such people include artists, government officials, academics, etc.

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These organizations also host screenings on college campuses about the rights of people with diffabilities, with the hopes that more people with become involved with the diffability movement for an inclusive society in Indonesia.

Though the social model has made great strides in improving the lives of people with disabilities, as it encouraged the removal of social barriers, it does not come without criticism. The social model focuses on the environmental and social barriers as the main contributor to the oppression of people with disabilities. However, many argue that oppression, as a nebulous concept is poorly understood and undertheorized in the sense that little is known of how oppression influences the relationships between culture, language, and socialization (Owens, 2015; Hughes, 1999; Imrie, 1997; Shakespeare, 1995), especially in how it relates to people with diff-abilities (Owens, 2015). Furthermore, the social model of disability is a Western theorized concept and according to Barton and Armstrong (2001), the universal values found within the conceptualization of diffability, such as human rights, equality, and justice, may not translate the same in the Indonesian context. Therefore, this concept leaves some critics arguing that it is unable to adequately capture how culture, language, and socialization contribute to and perpetuate the oppression of people with disabilities (Hughes, 1999; Imrie, 1997; Shakespeare, 1994; Owens, 2015). As a result, the experiences of diffablement are not adequately being captured, leaving an incomplete understanding of the complexity of diffablement.

As one can see, Indonesia is a highly pluralized and complex society with multiple belief systems involved in the creation of the views in which society here

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conceptualizes diffabilities. Therefore, when discussing, theorizing, and working towards

a more inclusive society for people with diffabilities in Indonesia, one must have a better,

more holistic understanding how these belief systems operate to create change that is

accepted by the general population. Though this chapter has discussed for of the most

prominent belief systems operating in the Muslim population of Indonesia today which

outline how people with diffabilities have been and should be viewed, one must keep in

mind that these belief systems, however powerful in influencing people's

conceptualizations of people with diffabilities, the strength of these beliefs will vary with

each family and each individual.

CHAPTER 5: DIFFABILITIES AND GOVERNMENT POLICIES

In the previous chapter, the four differing conceptions of diffability that operate within Jogja that shape how people view people with bodily differences were discussed. Within this chapter, I follow up the previous discussion with contested government policies and conceptions of people with diffabilities found throughout Indonesia as it pertains to education, employment, and healthcare. Background knowledge of education and employment serve as a backdrop to the overall infrastructural violence and socio-spatial exclusion of people with diffabilities in Jogja. This background is relevant because one cannot merely talk about diffability without a full understanding of the overall oppression faced by those living with a diffability as these previous experiences go on to shape and influence people's future experiences with people with diffabilities. have with their built and social environment.

The point in briefly exploring other aspects of oppression Javanese people with diffabilities experiences gives the reader a better sense of what it is like "being-in-the-world," a notion first introduced by Heidegger (2008), as a person with a diffability. Heidegger's intention was not only to move past the Cartesian mind-body dualism with this idea of being-in-the-world but to prioritize and shed light on people and people's experiences subjectively (Dreyfus, 2009). Therefore, the notion of being-in-the-world can be seen as "a structure which is primordially and constantly whole" (Heidegger, 2008, p. 225). "Being-in-the-world suggests a holistic understanding of human being that does not

abstract an individual from the context s/he inhabits" (Mladenov, 2016, p. 10). Linking

this idea of being-in-the-world and my work on place and space with people with

diffabilities experiences of being-in-the-world, we can better understand that one cannot

just be seen as a "being" occupying, or not occupying "space," but rather a "beings"

involvement with an understanding of "space."

Involvement with an understanding of "space" is important as Heidegger points

out, being-in-the-world is a state in which one enters when they begin to make sense of

oneself and others about "space." Being-in-the-world can be thought of as "a condition

into which human beings enter, either individually or collectively, at a historical juncture

when Being becomes an issue for them" (Fried and Polt, 2000, p. xii). Furthermore,

Merleau-Ponty points out that the "phenomenal body" (chapter 4), is different than the

"objective body" insomuch that the "phenomenal body" is the "lived body," as in that the

body already has a relationship with the world. In other words, "I am conscious of my

body via the world," but also "I am conscious of the world through the medium of my

body" (Mladenov, 2016, p. 13). This consciousness within the field of phenomenology

> "…. help to advance weak bodily realism beyond binaries such as body
>
> versus society that have impaired conceptually the social model of
>
> disability. From this perspective, meaning emerges out of the
>
> interrelations among humans and entities in a meaning-engendering
>
> context or world that extends from future projections to past histories.
>
> Yet is only after meaning has emerged that we can identify humans,
>
> entities, and their interrelations as such" (Mladenov, 2016, p. 59).

Based on the idea that we must understand the "lived body" to understand the overall oppression people with diffabilities face in Jogja is supported by the field of disability studies. According to this field, one must take "a holistic approach that explains specific problems experienced by disabled people regarding the totality of disabling environments and cultures" (Barnes, 2007, p. 350). So, to begin, I argue that exploring experiences of education, employment, and health in regard to people with diffabilities is vital to understanding the experiences of infrastructural violence and socio-spatial exclusion of those with bodily differences.

Understanding the "lived body" and creating a holistic understanding of the experiences of infrastructural violence and socio-spatial exclusion of people with diffabilities in Jogja, one must start from the beginning when life experiences shape and form our current understandings of our experiences. With stigmas, bullying, and lack of quality education for people with diffabilities in Indonesia, it is no surprise why many families continue to hide away family members with a diffability, why communities often shun them, and government services, policies and job opportunities quickly become out of reach (Interview with Lestari, 2016). As a result of unequal life chances, many people with diff-abilities sink into deep depressions as they are forced to remain at home, hidden from the outside world.

Experiences with depression and anger from being forced to live with a diffability in an environment that cares and understands little about them is something both Lestari and Alimenia openly discussed with me. For Lestari, after her accident, she fell into a

deep depression that forced her to spend the next ten years at home spending her time

embroidering indoors; where she remained until she discovered and acquired her

modified motorbike[6]. Alimenia explained how she blamed God for some 20 years for

contracting polio making her different from other kids as it meant she needed to use a

wheelchair instead of her own two feet to move around her environment. It was not until

her mid-20s that she said she finally came to terms with the fact she contracted polio and

using a wheelchair was going to be a permanent part of her life.

Article 281 in Indonesia's constitution of 1945 states that

> "Every person shall have the right to be free from discriminative
>
> treatment based upon any grounds whatsoever and shall have the right
>
> to protection from such discriminative treatment" (Paragraph 2, Article
>
> 281).

However, regardless of Article 281, many diffability activists believe that

Indonesia continues to not follow through with this promise of being free from

discrimination nor does it provide does much in the way of employment aid for people

living with physical or mental diff-abilities. In one of my many discussions with Lestari

and Alimenia, they explained that life continues to be an everyday struggle for survival,

even after concurring their depression and anger. Like many others, Lestari and Alimenia

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[6] See example 1. Lestari's modified motorbike includes a ramp and platform for her
wheelchair, additional wheels to support her wheelchair, relocated handlebars, and hand
controlled stick shift and breaks.

believed at one time that their diffability stripped them of all their independence. For Lestari, this loss of autonomy meant spending lot of time stressed about not having a job. She said, "I was constantly worried about [not having a job] and being really dependent on my parents, so I as so worried about a job" (Interview with Lestari, 2016).

The oppression of people with diffabilities in Indonesia is nothing new, however, with the relatively recent grassroots movements, mainly in Jogja, the Indonesian government responded by renewing its signatory of the International Convention on the Rights of People with Disabilities (CRPD). Before resigning the 2011 CRPD, Indonesia enacted Law No. 4/1997 on Disabled People that states that companies with more than 100 employees, must have a one percent employment rate for people with diffabilities (Liu and Brown, 2015). Furthermore, as of 2015, Indonesia has 17 more laws citing the rights of people with diffabilities. However, many diffability activists argue that Indonesia only has a basic framework regarding the rights of people with diffabilities and even within this basic structure, there are significant gaps between what is outlined on paper as laws and what is being implemented on the ground (Lestari, 2016, personal communication).

Through the narratives shared to me in regard to living with a diffability in Indonesia, experiences with employment, education, and health played a central role in the development of identity and how they viewed the world as every person I talked with discussed these issues in length.

Employment and People with Diffabilities

In 2016 Indonesia's diffability activists celebrated what is considered the historical new Law No. 8/2016 passed on 18 April 2016 that further promotes equal rights for persons with diffabilities, including the right to seek and maintain employment. The following year, Law No. 4/1997, discussed briefly at the beginning of this chapter, was enacted that states that companies with more than 100 employees, must have a one percent employment rate for people with diffabilities (Liu and Brown, 2015). However, the many activists interviewed, stated that companies do not follow this law nor does anyone follow up with companies with more than 100 employees to ensure they are hiring at least one percent of people with diffabilities (Lestari, 2016), leaving people with diffabilities with an empty celebration of the creation of these two laws. Many companies cite high costs and expenses that they must cover to provide adequate accommodations for people with diffabilities as their reasoning behind not hiring them.

According to the World Health Organization (WHO) and the World Bank (2011) in a collaborative research project focusing on employment of people with diffabilities in 51 countries. The results showed a general trend of both male and female workers with diffabilities being hired less often than male and female workers without diffabilities. However, among persons with diffabilities, men with diffabilities were given priority over women with or without diffabilities when it came to employment by nearly 30 points (*World Health Survey,* 2011).

Within Indonesia, employment of people with diffabilities can be seen through data collected in a 2010 Census that shows the working status of the population between

18 and 64 and the degree of diffability, education, and gender.

Table 1.2:
Employment and Diffabilities

	Status/Degree	Working Status	
		Employed	Unemployed
Degree of Diffability	None	64.11	35.89
	Light/Middle	53.36	43.64
	Heavy	26.42	73.58
Educational Standard	Not Finished Primary	64.95	35.05
	Primary Graduate	65.67	34.33
	Secondary Graduate	62.68	37.32
Gender	Male	83.35	16.65
	Female	43.94	56.04

Source: Demographic Institute, Faculty of Economics and Management, University of Indonesia, Survey on the Need for Social Assistance Programs for People with Disabilities (SNSAP-PWD) 2012

This high unemployment rate experienced by people with diffabilities leaves them and their families living with high rates of poverty throughout Indonesia (JICA, 2015). So often, the unemployment of people with diffabilities in Indonesia stems from the negative beliefs and stereotypes of people with diffabilities as well as the lack of quality

education. Furthermore, unemployment of people with diffabilities contributes to overall stigmatization and oppression they experience on a daily basis regardless of numerous laws that are written to protect their right to work, such as:

The "Recognition of the persons with disabilities' rights to work and to live ordinary and peaceful lives according to their degree of disabilities and educational backgrounds (Paragraph 2, Article 6; Paragraph 2, Article 12).

"Every persons with disabilities has the right of equal employment opportunity, depending upon the type and degree of the one's disability" (Article 13), and lastly, "state and private enterprises shall provide equal opportunities and treatment for persons with disabilities on occasion of hiring employees. Determination of employment is made by the employer with reference to the type and degree of disability, education, qualification and ability of the candidates." (Article 14).

Despite these laws, Indonesia still sees a high rate of unemployment among those with diffabilities as seen in figure 2. The worry of not having a way to provide for oneself is something people with diffabilities from all over the world experience. However, in places like Jogja, as discussed in chapter four, not only are children expected to provide for themselves and their immediate families when they grow up, they are supposed to then provide for their parents as well as their parents provided for them. This cycle of providing for family members leaves people with diffabilities that much more worried about future employment. Furthermore, as discussed in the next section, most of the education people with diffabilities receive that of trades that they can sell in the

marketplace. Though many of the people with diffabilities do become skilled in a particular area, they are often unable to get into the city to the market to sell their goods, thus leaving them in the vicious cycle of poverty (Lestari, 2016) and hence the reason it is essential to understanding infrastructural violence in Jogja.

Education and Students with Diffabilities

During a casual conversation, I was engaged in with both Alimenia and Lestari outside of my homestay one morning the topic of the importance of children with diffabilities receiving a quality education came up. Though both women had different experiences with education growing up (Alimenia attending a school for the diffabled in Solo and Lestari attending a public school), both women agreed that accessing quality education for children with diffabilities in Indonesia, including the education capital of the country, Jogja, continues to pose a challenge. A large of this difficulty stems from the Dutch colonial legacy, Indonesia's school policies pull from modern medical practices and state that children in primary education and adults in higher education must meet certain health conditions such as being mentally and physically healthy to attend. As a result, the typical child with a diffability is sent to a special school that is said to meet their needs.

However, many diffability activists continue to argue that the majority of children with diffabilities receive no education at all as attending school, even for a school for the diffabled, is mostly inaccessible. Not attending school due to them being inaccessible goes against Indonesia's law of equal rights to education for all citizens (Law No. 4, 1997; Constitution: Paragraph 1 Article 27, Paragraph 1, Article 28D, Paragraph 1 Article

31) (JICA, 2015). "Moreover, the governmental budget for the education of the [diffabled] and general lack of assistive technology exacerbates these problems" (Thohari, 2013, p. 98). Those in government counteract this argument by suggesting that Indonesia is meeting the laws on equal access to education by providing hundreds of schools specially designed for children with diffabilities. However, once again activists push back on this argument because these schools wind up further segregating these children with diffabilities from "normal society" where they do not receive the same education, but rather an education based on skilled work like sewing, carving, and painting (Lestari and Alimenia, 2016).

During a trip with Alimenia to Solo, Indonesia, which is about a 45-minute train ride from Jogja, Alimenia and I visited her old primary school where she spent most of her childhood alongside many other polio survivors. During Alimenia's childhood, students with diffabilities were sent away to special schools where not only they received vocational training, but they were expected to live there as well in between holiday breaks. After giving me a tour of her old school Alimenia discussed some of the major issues with the schools for diffabled children in Indonesia. For one, Alimenia talked about corruption from those running the schools. She also mentioned that most, if not all schools for diffabled children are underfunded and understaffed and those who were hired to work there to both teach and take care of the children, are not sufficiently educated to work with children with diffabilities.

After walking around and getting a tour of the grounds, Alimenia and I stopped in a hallway to talk about some very personal experiences she had as a child living at this

school. Alimenia mentioned that though schools for children are still limited in number, it was worse when she was a child. Attending school for her meant leaving her hometown in Bogor, Indonesia (West Java) and traveling to and living in Solo, which was commonplace for just about all of her schoolmates.

As both a mother who was born and raised in the United States living in an upper-middle-class white family, the idea of having to send my child off to a special boarding school to receive an education that was not even equivalent to my child's peers deeply bothered me. Being able to see my child every day, talk about how their day at school went, help with homework and meet and talk with their teachers was a privilege of mine that I had not been conscious of till that moment. Out of both shock and curiosity, I wanted to understand more about how Alimenia felt about spending most of her childhood apart from her family and why parents make this choice for their children. However, after starting a conversation about this, it was clear that this topic was off limits with Alimenia to a certain degree. Once I had finished talking and asking questions about this experience, there was an awkward silence, and immediately Alimenia's body language turned from a happy, comfortable eagerness to educate me to be rigid and a loss of all eye contact as she stared at the concrete beneath us. In fact, after a few moments of this silence, Alimenia began discussion her joy of sneaking out of the school and playing with the stray dogs outside.

Out of respect for Alimenia, I backed off this question and engaged her in conversation about her love of animals as her silence answered my question as to how she felt about this experience of living at a boarding school for children with diffabilities.

Soon after, however, Alimenia looked at me for a few seconds in silence and said without emotion:

"I believe parents send their disabled children to these special schools to help teach their disabled child independence out of the desire to get rid of them. If a disabled child is to survive in this country, you must force them to learn how to move around by their selves, feed themselves, and speak up for themselves and this is what being sent away to a special school teaches these children. It is important to learn these skills as a disabled person, because when you grow up to be a disabled adult, people will be less likely to cater to your needs" (Alimenia, 2016).

Though obviously hurt by her experiences here at this school, Alimenia said, in a matter-of-fact way, that she preferred it this way as she was able to be around people like herself and learn how to care for herself and be independent. She would not be where she is today without that experience. I want to add here that sending children away to school is not just an experience for those with diffabilities in Indonesia. Here, it continues to be common place for children living in more isolated areas where there may not be a local secondary school to be sent off to a boarding school or live with relatives in a provincial capital. Also, Many Muslim children are also sent to Muslim boarding schools called pesantren.

After a brief moment of silence, Alimenia went back to discussing the reasons why parents of children with diffabilities wanted to send their kids to these schools as a

way of "getting rid of them." Alimenia believes that sending their child/ren to these schools is done because of not wanting to care for the child/children; the parents cannot afford a child with a diffability, or the social stigma of having a child with a diffability in their family. According to Alimenia, during her time in primary school, she had a few friends who's lived experiences were not being wanted by their parents. When school holidays arrived, these friends were forced to remain at the school alone while they watched their classmates be picked up by their parents or taken by school staff to a train station to be sent home. For Alimenia, these holidays were both a time of excitement as well as sadness for her because "it was nice to see [her] parents and family again, but [she] had to leave [her] friends behind knowing that they were not wanted by their families" (Alimenia, 2016). Furthermore, Alimenia said "back when I was in school, there was nothing you could do if your parents didn't want you, but today, the government makes you take them back" (Alimenia, 2016).

Though this practice of sending your child to a special school for the diffabled and never returning to pick them up occurred more often during Alimenia's childhood than it does today, one can still find happening today. According to both Alimenia and Lestari (2016), to combat the problem of parents abandoning their child/ren at schools for the diffabled, the Indonesian government pays the cost of putting abandoned children on a train and sending them back to their families, essentially forcing the parents to care for them. However, on occasion, the parents send their child off to school and then pack up their belongings and move, without a trace of evidence as to where they moved to. As a result, the government attempts to track these parents down to have the child cared for. If

the parents are nowhere to be found, next of kin is forced to take over the task of caring for the child. Though today the practice of abandoning children has been drastically reduced, it calls into question whether or not children forced to be cared for by unwilling parents or family members experience a significant increase in mental, emotional, and physical violence at the hands of family members. A question that is thesis is unfortunately not designed to answer.

Upon returning to Jogja, my daughter and I went for a walk through Malioboro Market Place with our friend and guide. It was a humid, rainy night and my guide asked me how my research was going and if I had got at least some of the information I was seeking. I responded by telling her that I had received more information that I had ever expected, but more important; I have met some of the strongest and most resilient people I have ever known. I also described the confused and hurt feelings that I got from learning about how Indonesian parents with children with diffabilities had to send their children off to boarding schools and as a mother, I did not know if I could do that.

After a few minutes of silence, my guide looked at me and quietly said, "my sister was born multiple sclerosis and then contracted polio as a young child" (personal communication, 2016). My guide then went on to talk about what it was like witnessing the cruelty of the other children towards her sister. She went on to further mentioned that she believes that sending children with diffabilities to special schools is also a form of protection from experiencing bullying and violence from other children based off of the numerous rumors and stigmas discussed in chapter four. In support of my guide's experience with witnessing her sister be bullied by other children, Alimenia, in a future

discussion, talked about her attempts at integrating into mainstream education when she was a little older, and Indonesia adopted the Inclusive School Act. She went into great detail about the bullying and violence she experienced from her peers.

To support Sani's experience, Alimenia talked about being bullied in a public school after leaving her special school when Indonesia adopted the Inclusive School Act, which was not put into law till 2003 (Law No. 70) and formally adopted in 2009. The Inclusive School Act in Indonesia states that in Indonesia unequivocally guarantees that every citizen has a right to formal education regardless of physical and cognitive ability (Poernomo, 2016). Though this concept of full inclusion in mainstream education was a concept that was promoted internationally for over a decade, in Indonesia, students with diffabilities continue to face multiple barriers to full participation and inclusion within mainstream education systems.

"Lack of information, combined with discriminatory attitudes towards persons with disabilities at all levels of society contributes to the continued neglect of their right to education" (Poernomo, 2016, p. 144). For this reason, the Indonesian government started pilot programs in 2002 in nine provinces and by 2005 nearly 6,000 students with diffabilities entering mainstream education in Indonesia (Poernomo, 2016). In Jogja specifically, most mainstream schools are still inaccessible and do not accept students with diffabilities, but are actively moving towards a more inclusive environment. As of today, the Inclusive Schools Act mandates that each town or regency must have one appointed elementary or junior high school that is inclusive to students with diffabilities and in Jogja, the result is shown in a table designed by Thohari (2003).

Table 1:
Types of Schools in Jogja

	Special Schools	**Inclusive Schools**	**Public Schools**
National	2,627	640	191,422
Jogja	59	62	5,012

Source: Thohari (2013)

Thought each town or regency must have a minimum of one elementary or junior high school that is inclusive, in places like Jogja it does not solve the problem of people experiencing a lack of proper accessibility to and from school, especially in rural areas. Furthermore, by having one school that is appointed as an inclusive school, children with diffabilities are once again be segregated into that specific school. The segregation is a direct result of the belief that inclusive schools provide poor education, causing parents to move their children without diffabilities to non-inclusive schools where the education is believed to be better. Therefore, school administrators in Jogja do not wish to have their school be turned into an inclusive school as many of the schools in Jogja are engaged in a battle to be seen as the best school in the area.

According to Alimenia this causes students with diffabilities entering into mainstream schools forced to be inclusive often experience discrimination and abuse by teachers and staff and do not experience bullying or violence from other students. In her

experience as a child in mainstream education, Alimenia recalled times when other kids

pulled her hair, spit on her, called her names and sometimes even kicked her crutches out

from underneath her, causing her to fall to the ground while the other kids stood around

laughing. Furthermore, Alimenia could not rely on the administration to keep her safe

while attending school as those in administrative positions tried to push her out of their

school on a continual basis. Administration officials continually tried to make the school

building less accessible for her by placing her classes on the second or third floor, making

it challenging for her to ascend the stairs to her classroom.

In a 2001 study conducted in the West by the National Institute of Child Health

and Human Development, researchers found that nearly three out of ten children are

affected by bullying. Though research is limited on bullying of children with diff-

abilities, Whitney, Smith, and Thompson (1994) suggest that students with diff-abilities

are likely to experience higher rates of bullying than non-disabled children. Children with

physical diff-abilities "are likely to move slower, have less stamina, have an unsteady

gait, and in some cases maybe non-ambulatory" (Flynt, and Morton, 2004, p. 332).

Research suggests that these conditions are often labeled as and seen as weakness, which

bullies then use to inflict verbal or physical abuse.

Discrimination in Indonesia's education setting does not begin and end with

primary school, but continues in higher education. Very few colleges in Indonesia will

accept people with diffabilities as they believe college courses will be far too difficult for

a person with physical or mental limitations and that these limitations will also disrupt

both the teaching and learning process in the classroom (Sholeh, 2015). Not being fully

accepted or accepted in higher education is something to which Alimenia can attest to. Alimenia, a graduate student of psychology attending Gadjah Mada University (UGM) in Jogja, testifies that through her school's administrators at UGM are supportive of her presence there, not all her professors feel the same, which I found out during a tour she gave me of her university.

UGM is a place Alimenia is proud to call her university as the university continues to be one of the more welcoming and encouraging of all students with diffabilities. Alimenia was eager to show me the ramps, elevators, and accessible bathrooms that UGM had recently installed that made her life and accessibility to higher education not only welcoming but easier. Elevators in Indonesia, especially Jogja are a rare find, so as a person with a physical diffability, I too was elated to see one. During my five weeks in Indonesia, the only other time I had seen an elevator in Indonesia was at my western hotel in Bali and at the mall, where one had to climb up three stairs to access.

Upon the completion of the tour, Alimenia and I discussed her struggles with social acceptance among some of her professors at the university. Alimenia described one interaction with a professor as "hurtful, but nothing new" as the professor called her "stupid and she should not be forced to teach a person with a disability as it is a waste of her time" (Personal communication with Alimenia, 2016). Other times, professors felt as though being in a wheelchair was a distraction to other students and asked for her to be removed from their classrooms, though their attempts to do so failed. Alimenia has even struggled with receiving poor grades on assignments completed well and faculty refusing to accept any of her thesis proposals in what Alimenia believes are attempts to force her

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out of the university (Personal communication with Alimenia, 2016). Though Alimenia says she is tired of the treatment, she refuses to let her professors make her quit as she has been fighting this discrimination to quality education her entire life.

Education in Indonesia for all children, but especially for those with diffabilities, is an early introduction to what it is like being-in-the-world. For children, their lived experiences throughout primary school help shape and form future perceptions of what it is like to live in and interact with those in your world that ultimately perpetuate inclusivity or discrimination. By better understanding how educational settings contribute to the understandings by people with diffabilities of "space" and being-in-the-world contributes to self-recognition and understanding help us better acknowledge their future perceptions of social interactions, socio-spatial exclusion, and infrastructural violence experienced later in life.

Health Policies for People with Diffabilities

Due to inadequate education, insufficient monetary income, and Javanese culture, many people with diffabilities are dependent upon either their parents or children for support. For families below the poverty line, when a family member with a diffability has a medical emergency, it is often disastrous for families. Though this trend is seen throughout the world, the poverty that people with diffabilities face in Indonesia is just as severe as any other part of the globe. Indonesia currently has set up diffability policies that are integrated throughout their National Plan of Action. However, Indonesia continues to lack the human resources in the medical and rehabilitation field about the

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existing needs of the people living with diffabilities in Indonesia (Kusumastuti, Pradanasari, and Ratnawati, 2014). Moreover, the health facilities that do provide services that are covered by government aid are considered unreliable in recognizing the needs of people with diffabilities (Thohari, 2013).

As outlined in chapter four, the medical model of disability that was introduced through the Dutch colonialization is still a mainstay when it comes to addressing the issue of diffability in Indonesia. However, rehabilitation in the medical sense is still unrecognized at all levels of society as diffability rehabilitation is legally seen solely as a social affair as outlined in Article 1 paragraph 4 of the Government Regulation No. 36 of 1980 (Kusumastuti, Pradanasari, and Ratnawati, 2014; JICA, 2015). Recently, however, the government declared that rehabilitative medical needs should be provided in all government hospitals in a way that all citizens can access the services, though it is not stated in law or been accepted by most local areas.

This lack of accessible rehabilitative coverage in local areas leaves people with physical diffabilities with no option but to travel to big cities for comprehensive medical rehabilitation as most specialists in rehabilitative medicine work in the big cities on Java island. Not only do these specialists work mainly on the big island of Java, as of 2014, but there were just 380 people qualified to work in the field of medical rehabilitation (Kusumastuti, Pradanasari, and Ratnawati, 2014). This traveling to the big city for most people with diffabilities this means an entire family is missing a day of work for one family member to receive the medical care they need. A prime example of how this is detrimental to the entire family comes from a woman I met in Lestari's village who

suffered a spinal injury after falling at her family home that left her paralyzed from the chest down. Through the pain of muscle spasms in her legs, bed sores, and the misunderstanding that exercises will not cure her, the woman described what it was like traveling to the big city every two weeks to have her catheter changed by a qualified nurse.

Living in a remote part of a rural village and needing constant medical care, for this woman, means the entire family has to come together and miss an entire day's work for her to survive. Getting her to the hospital requires two people and a motorbike as a cab, which is not only unaffordable for the family, cannot access the rocky and uneven dirt road leading to their house in the village. As a result, the woman must be cradled in the arms of either her adult son, daughter, or husband on the back of a motorbike while the other drives to the hospital. This is a challenging task for anyone, let alone a woman who rife with pain and has no control over much of her body.

The journey takes a few excruciating hours, once arriving at the big city hospital, the family is forced to wait a few more hours before the catheter can be changed by an available nurse. Afterwards, they embark back on their journey home in the same manner in which they arrived, one person driving and the other cradling the woman on the back of the family's sole form of transportation, a half broke down motorbike. The entire day has been lost because there are no local hospitals near their village in Jogja that employ a nurse who is qualified to change the catheter. This results in a day's loss of work for a family that is already struggling to survive with one able-bodied person doing all the work in the rice fields while one of the adult children stays home to care for the woman.

If the local hospital or healthcare facility employed at least one qualified nurse, more families like the one belonging to this woman would not have to take a day off work, which risks their survival, to seek life-saving medical care.

Even with the lack of qualified care in local areas being a recognized as a concern for many, medical rehabilitation services found in hospitals continue to neglect individual medical care that focuses on specific diffabilities an instead makes medical rehabilitation a one size fits all program. For example, if an elderly man with a spinal injury arrived at the hospital for treatment of his injury, he would receive the same rehabilitative care as a child who could not walk due to complications from polio. Furthermore, people with diffabilities, these health services are said to be covered by government insurance, but this insurance not cover rehabilitative aids that help people be ambulatory such as wheelchairs, canes, walkers, orthotics, or prosthetics. Furthermore, many of the people with diffabilities I spoke with mentioned how this insurance barely covered their other medical needs.

The two primary governmental systems for health security to which people with diffabilities should be able to access in Indonesia are Askeskin (Asuransi Kesehatan Masyarakat Miskin; Health Insurance for the Poor) and Askesda (Asuransi Kesehatan Daerah; Regional Health Insurance), in Jogja, this system is known locally as Jamkessos (Jaminan Kesehatan Sosial or Social Health Security) system. Recently, however, Indonesia's government launched a new health insurance system called, Jamian Kesehatan Nasional (JKN), with the goal of improving the lives of those too poor to afford health insurance, but considered not poor enough for government aid.

On paper these government health care systems seem beneficial, however, more often than not, they lack their intended purpose. Nationally, Askeskin program faces high rates of corruption and a culture of collusion that prevents its services from reaching many of the people it is intended to help as much of its funds go to benefiting the middle class rather than the poor (Thohari, 2013). Some argue that this corruption is made possible by not having a clear outline as to who should be classified as "poor," and more importantly, does not cite people with diffabilities as being in the target population.

Furthermore, on the local side, the Jamkesmas program also does not identify people with diffabilities as being a target group residing in the population of poor people. Though it is important to recognize that not all people with diffabilities in Indonesia are economically poor, it only takes one incident to cause one to become economically poor in Indonesia. Lastly, According to UGM's Center for Health and the Paramadina Graduate School of Diplomacy, JKN's plan is too ambitious and not effective in areas where people are isolated and traveling to a clinic or hospital involves long and often expensive journeys to urban areas.

During my time in Jogja, it became clear pretty quickly that people with diffabilities often do not enjoy equal access to health care, health insurance, or even protection to health care under the law as the average citizen. All too often the health care needed by persons with diffabilities are not covered under the government health insurance programs if one is even able to benefit from them, "thus leading to exclusion on the basis of [diffability]" (Thohari, 2013). This lack of accessibility to heath care stems from both socio-cultural issues as well as an inaccessible environment and thus

directly relates to the importance of this thesis as it investigates socio-spatial exclusion

and infrastructural violence against people with physical diffabilities in Jogja.

CHAPTER 6: RIGHTS TO THE CITY: INFRASTRUCTURE AS VIOLENCE

One of the most significant elements of people with diffabilities lives living in Jogja and to which this thesis is based is that of accessibility in public spaces. This chapter intends to capture the everyday experiences of diffability and accessibility within the physical space of Jogja. Throughout this chapter I argue that the built physical landscape acts as a form of segregation the separates those with bodily differences from those who are deemed "normal" and I support this argument through the use of socio-spatial theory, which comes from the field of human geography and Bourdieu's sociological theory of *habitus.* Through these social theories I am better able to expose the micro and macro level of marginalization of people with physical diffabilities that exists in Jogja that dictate who is and who is not allowed to occupy certain social spaces.

Jogja, in general, is a city where public places continue to not meet international standards of accessibility despite renewing its signatory of the CRPD and vamping up their own domestic laws. As seen in previous chapters, accessibility to and through the city of Jogja is challenging and creates a form of segregation against people with physical diffabilities. This segregation through the use of the built physical landscape is what I call, infrastructural violence which perpetuates the control and containment of bodies considered undesirable (socio-spatial exclusion).

Throughout this chapter, I rely on the everyday experiences of Alimenia as she travels through traditional marketplaces, office buildings, parking places, restaurants, and

public transportation. For this, I hope to bring the reader closer to understanding her true struggle as I documented much of these experiences through the use of ethnographic photography which further illustrates the dire situation people with diffabilities face when attempting to access the city of Jogja.

Visual Ethnography

Urban photography has an extensive history in artistic and popular traditions as a form of street art as photographers capture the everyday lives of individuals who occupy specific localities. However, urban photography has increasingly become more popular among ethnographers and geographers as it has shown the potential as a promising methodological tool in social research. This potential allows readers/viewers "a way to understand the culture of the community under investigation, as well as a way to understand photography as a medium of communication" (Schwartz, 1989, p. 152). Ethnographic photography is a medium that ultimately blurs the line between what is art is not academic and what is academic is not art. For this reason, to use pictures as a form of data or data generators, one must have a better understanding of how viewers treat and understand photographic images and how I came to use my pastime hobby as a way to capture intimate moments between a woman and her built environment.

When I first embarked on this journey into the world of diffability in Jogja, I never fathomed my camera would become one of the primary modes to which I collected data for my research. I initally brought it along to capture moments in time with my daughter as we explored Indonesia. It was not until one day I brought my camera with me

on an outing with Alimenia that I was made accidentally aware of how important it would become to my work there. Upon seeing my camera, Alimenia began insisting that I take pictures of everywhere we went as we explored the city of Jogja and traveled by train to Solo. I happily obliged without giving it much thought being ignorant the importance of these photos in this work.

However, the use of visual ethnography as a methodology within research does not come without difficulty. Ruby (1973, 1976) states that many who engage in photography as a research tool are unaware of the social implications that come with it. Though this research is dated, the statement has room to stand as each time one captures an image with a camera; they are reproducing an image that can be used to reproduce systematic violence against the very people we are claiming to help. According to Scott (2007), street photographers claim to capture "moments of the bizarre, strange, intriguing" (p. 88) but all too often they fail to see how their work contributes to the overriding machismo and objectification they desperately try to avoid.

Therefore, street photography is criticized by many as engaging in the exotic and comical over the political (Halliday, 2012) as the photographer allows for "the viewer to remain in control, positioned as somewhat distant from and superior to what the images show us" (Rose, 2001, p. 22). Though this kind of control is what I fought to avoid in my work, it has me questioning whether or not one can ever fully prevent it?

The use of photography as a form of visual representation, as argued by my geographers, allows for us to rethink everyday spaces. The photographs are meant to elicit conversations as they adopt a "critical awareness of poststructuralist critique while

embracing the potentialities of photography" (Hunt, 2014, p. 155). Therefore, through the images I captured of Alimenia's experiences as she moved throughout the cities of Jogja and Solo, I attempt to highlight the agency of place and space, hierarchy, and "engagement with creative practice and place through the body" (Hunt, 2014, p. 155). Further potential for complication and misrepresentation through the use of photography in my work includes the ethical use of photographing diffability.

Captured in a profound quote, Emily Post (1978) asks:

"How do you behave around disabled individuals? The answer is, ideally, you behave just as you would around a person who has no visible handicap. Never stare…." (p. 54).

This quote resonates with me, as I am sure does with most of those reading this thesis, because as a child that was one of the first things I remember being taught by my mother, "it is not polite to stare at people, especially people with diffabilities." Furthermore, as I experienced my first surgery on both of my feet as a way to reconstruct my high arches due to my own diffability, I found myself hyperaware of how people looked at me, stared at me and gave me what I would describe as pity or condescending looks for being in a wheelchair. As a result, I have spent most of my life avoiding looking at people with diffabilities for extended periods of time outside of having a personal conversation with that individual.

When it comes to photography, however, the very act of placing a person with a diffability into a photograph not only induce intense staring, but also records "that

person's physical impairment for posterity" (Hung, 2001, p. 399). Therefore, the idea that people with diffabilities can only be stared at offensively is something disability studies challenges as it implies that a body with a visible diffability cannot be visually enjoyed and therefore not innocently photographed (Hung, 2001). Though I intend to stay away from rationalizing my use of photos of Alimenia, as I believe it is imperative to view her as she is, my focus is not on her diffability its self, but rather how she experiences her built and social environment as a woman with a physical diffability.

Therefore, I argue that photography used as a methodology should not be seen as objective evidence as doing so "ignores the convention-bound processes of both image making and interpretation" (Schwartz, 1989, p. 120). Within my work, the literal snap of my cameras shutter not only irrevocably captured moments in time, but offers insight into infrastructural encounters as they are experienced by people with physical diffabilities and their relationships with place and space in a way that eventually contributes to the creation of one's identity.

Infrastructure and the Javanese

The streets of Jogja are where the majority of people spend most of their days, as a result, these streets are often overcrowded, and often poorly maintained. As I traveled down these streets day in and day out, with walking being my primary mode of transportation here in Jogja, I was overcome with the aroma of Javanese food as the streets are lined with numerous carts selling food. As I continue walking, I notice an array of different vendors following me as I weaved between the hundreds of tricycles,

pedicabs, motorbikes, and taxis lining the side of the road and people waiting around to catch the bus or buy their produce for next day meals. Also lining the streets are modern facilities such as dentist offices, clothing stores and beauty stores. At night, street lighting illuminates the dark and yet still crowded streets, often forcing people who are on foot looking for a safe path around them.

Since life in Jogja largely involves being outdoors, most social settings between friends and families also occur here, which sheds light on how important accessible infrastructure is for Javanese people. For the most part, the Javanese people do not walk very far, they utilize private or public transportation instead. Unless there is a good reason, walking alone, even for short distances is not preferred and can even cause embarrassment, as the person can be seen by others as unsociable. Once again, these common and normal social interactions that occur day in and day out in Jogja calls for the need to have a social and built environment that is accessible for all people with diffabilities to have all their basic human needs fulfilled.

The failure to freely access public places or transportation regardless of physical ability in Jogja is in direct contradiction to the United Nations principle of accessibility. This principal states that, "People with disabilities can, without assistance, approach, enter, pass to and from, and make use of an area and its facilities without undue difficulties" (Economic and Social Commission for Asia and the Pacific, 2005, Chapter 2, Section B, p. 8). I want to highlight the term "without assistance" in the statement on accessibility given by the United Nations. The ability to move freely and independently to, through and from all facilities without the help of others was how each and every

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person I worked with defined the term "accessibility" and therefore it is seen as something inherently important when one design and plan a built-up environment. The ability to move freely and independently is something I encourage readers to keep in mind when reading this paper, viewing my photographs, and engaging with your environment.

The Sidewalk

The way in which the Jogja is infrastructurally designed has been and remains dire for Javanese citizens with diffabilities. In Jogja, nearly all public buildings and transportation and social spaces remain inaccessible for people with bodily differences making it arguably dangerous for them to venture out into the public space and thus, often feeling as though they are unable to engage in social activities leaving them feeling isolated and cut off from society. One of the first things that caught my attention as I walked around Jogja my first day there was how challenging it was to make use of the sidewalks. Though Jogja is not traditionally a "walking city," as most make use of their motorbikes and vehicles to get around the city, for those who are unable to engage in that specific privilege of mobility, find it daunting and dangerous to leave their house. This fear stems from the fact that many of Jogja's sidewalks lack ramps and are riddled with bumps, holes, and at times, a few feet of the sidewalk missing altogether, leaving a gaping hole leading to the sewer.

Figure 1:
The Sidewalk

On one of the many outings my daughter and I went on with Alimenia I was able to capture the condition of the sidewalk that she must use to access the bus she needs to take to get to the local marketplace where she buys food, clothing, and other necessities. In this image, it is easy to see just how dangerous the use of this sidewalk for Alimenia can be. Not only is she not strong enough to push her wheels up and over the holes that are created from the missing stepping stones alone, one wrong move and her wheelchair could easily flip over leaving her laying on the ground with possibly serious injuries. Much like the first photo of the sidewalk Alimenia need to use to access the bus, the following photo of her bus route you see how Alimenia is unable to use the sidewalk at all as it has too many curbs without ramps, preventing her from using the sidewalk

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altogether. The inability to make use of the sidewalk places her on the street which comes

with its inherent risks for anyone, but especially for someone in a wheelchair.

Image 2:
The Road

The inability to make use of the sidewalk places her on the street which comes

with its own inherent risks for anyone, but especially for someone in a wheelchair. As

someone in a wheelchair, Alimenia sit lower than a person who has the ability to stand,

making it difficult for people in cars and buses to see her moving down the street, putting

her in a potentially dangerous situation of being struck by a moving vehicle. The

movement down the street prompted me to begin a dialogue with her about moving down

the street:

Laura: It seems incredibly hard for you as a person who makes use of a wheelchair to do anything alone when leaving your house. Do you often have help when out running errands or going to school, or are you by yourself most of the time?

Alimenia: I'm alone, always alone! Other people don't go out of their way to help you. Only if you say 'please, please, please help me,' then they will help. But not from their heart.

Laura: If it's not coming from their heart, where is it coming from?

Alimenia: They don't have empathy. But I think this generation I see they are lacking empathy. I don't know what the teacher teach [sic] or how their parents raise [sick] them; I don't know. But young people are lacking empathy. It is different when I was at that age, and I was young. My teacher always talked about caring for people. About doing something together, but not anymore.

I found Alimenia's comments about empathy and her perception of a changing culture as it is tied to the treatment of people with diffabilities intriguing. Her comments follow Bourdieu's theory of habitus where Bourdieu argues that shared body of durable dispositions are a product of history where both individual and collective practices playout according to schemes found throughout history (Bourdieu, 1990). Therefore, according to Bourdieu, the trend of an increasing population that is lacking empathy for others as seen by Alimenia, can be argued as stemming from a person's early years

growing up in an environment that perhaps does not teach empathy as it did when Alimenia was a child which then extends to how one socializes with others when out in public.

In listening to Alimenia describe what she sees as the lack of empathy in others and how that has changed overtime regarding how people help each other, led to a further conversation on how the conditions of the sidewalks and lack of help contribute to how some people with diffabilities felt isolated and excluded from society. The fear of being injured or embarrassed while trying to make use of the sidewalk, Alimenia states that it leaves many people who use wheelchairs too scared to leave their homes (Alimenia, 2016). As a result of feeling as though they cannot leave their homes safely, many are left feeling as though they are not welcome in joining their peers in social spheres of society due solely to their bodily difference (Alimenia, 2016).

Bus Station

Javanese people who do not have access to private transportation such as a car or motorbike, such as those with diffabilities, rely on buses and taxis for transportation. In this section I focus on Alimenia's experiences with riding the bus around Jogja city. Transportation-related issues with riding the bus for those with diffabilities continue to be one of the most persistent and expensive barriers that people with diffabilities face. The unequal access to public transportation in Jogja reproduces the already existing economic inequality faced by Javanese people with diffabilities as employment is directly linked with the ability to move freely throughout the city (see chapter 5).

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On a sunny and humid Tuesday morning, Alimenia, my daughter, and I met at the house where she rented a room because I was invited to follower her around to witness her daily routine. Upon arriving at her house, I was met by a little old Javanese lady from behind the gated driveway of Alimenia's house. In a neighborhood not used to seeing a white Western lady and child wondering around looking for a house, the lady quickly and suspiciously started speaking to me, in what I presumed to be Javanese. When I could not respond to her, because I do not speak Javanese, she began to yell at me even louder and swat at me with a large bundle of leaves she was holding in her hand. As I put my hand up in defense against this large bundle of leaves, I kept saying "I'm sorry, I only speak English."

Finally, she stopped swatting me with her leaves and asked me, "Who you speak English with at my house?" I replied by saying, "Alimenia!" The woman looked confused and said, "Alimenia?!" There was a long pause and then all of a sudden, the woman said, "Alimenia!" and started motioning her hands and arms as if she was pushing a wheelchair. It was in that moment, I realized, Alimenia was and is not known by her given name and a human being worthy of acknowledgment, but rather the woman in the wheelchair. Her humanity stripped from her, and she was now reduced down to an action, a someone pushing themselves in a wheelchair. This right here, what I was witnessing, was the very stigma and dehumanization that all the people I worked with were describing.

It was early morning and Alimenia, my daughter, and I headed down the road to Alimenia's local bus stop for a trip into the city for a day at the market. On what should

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have been a short walk to the bus stop, Alimenia mentioned to me how excited and scared she was to take me to Jogja by bus. These feelings of both excitement and being scared prompted me to explore this further. After a few more questions Alimenia mentioned that the excitement came from a place of being able to put actions with the words and experiences people with diffabilities had been sharing with me while her feelings of being scared came from a place of putting herself in both social and physical danger as she forcibly placed herself in harm's way taking me out into public through the use of public transportation, something further explored in a proceeding chapter.

After navigating the sidewalk leading the bus stop we finally arrived. Upon arrival, I was disappointed to see how inaccessible the bus station was. Much like the one by Alimenia's house, bus stations in Jogja consist of a turnstile that must be taken apart for a wheelchair to enter and a ramp, which is often too steep for one to push a wheelchair up alone that leads to a rather thin platform where riders wait for the appropriate bus.

Figure 3:
Turn Style

Figure 4:
Bus Ramp

For the most part, people with diffabilities find it difficult to board the buses as they approach as the buses often stop feet away from the platform and hardly come to a complete stop before taking off again while other drivers refuse to allow a person with a diffability to board their bus altogether.

Riding the bus with Alimenia to the local marketplace allowed me to witness what the majority of people were saying about public transportation being not only inaccessible for people with diffabilities but downright dangerous. Safety while riding the bus is a constant concern for Alimenia since the buses are operated in a way that is best suited for the young able-bodied person. In Jogja, bus drivers profit off of the number of riders and therefore are incentivized to move as many people as they can as quickly as possible, even if that means cutting out safety measures which include coming to a complete stop close enough to a bus platform for people to safely enter and exit.

Figure 5:
Entering the Bus

In order for Alimenia to even enter the bus, she would need anywhere between two to four people to help lift her over the gap, thus removing her ability to move freely and independently from the bus platform to the bus itself. Furthermore, on more than one occasion, bus drivers who saw Alimenia gathering people to help her enter the bus, would simply drive the bus away, thus refusing to allow her on. Other times, drivers would become angry at how long it took her helpers to get her safely on the bus and would threaten to drive off while people had one foot on the bus and the other on the bus platform as a reason for them to hurry up. Once on the bus, there was no safe place for Alimenia to park her wheelchair, leaving her to hold onto the poles of the bus in hopes she did not roll while moving and stopping.

Figure 6:
On the Bus

For Alimenia, being forced to sit in the isle with no sufficient way to secure herself proved just how dangerous this is during one of our many outings. On this day, we entered the bus and found places to sit. As we were driving down the road someone on a motorbike abruptly cuts of the bus, we were riding on, causing the bus to make a near sudden stop. Everyone on the bus went flying forward, causing us to fall on top of one another. After finding my daughter under a pile of people who flew out of their seats and onto the floor I looked for Alimenia. I found her hanging onto another center pole and both mad and scared. Her wheelchair had gone from the back of the bus all the way to the front of the bus where she was fortunate enough to grab onto the last pole before rolling right out the open bus door. Alimenia quickly assured me, this was not the first time she has experienced such fear of rolling right off the bus.

Upon arriving at our location, I was interested in getting some of Alimenia's thoughts on the ride while they were still fresh. We found a nice shady bench sit down and talk. Below is a transcript of the conversation that took place.

Laura: Let's start off with talking about what your experience was like riding the bus to get to Malioboro (marketplace).

Alimenia: Which bus? The new bus, or the old bus?

Laura: All the buses we rode today, new and old.

Alimenia: Okay, talking about the old buses, they are not accessible at all, you know. Someone must carry me from the platform to the bus over the big hole, the big gap, you know? Almost twice I fell off (meaning they almost dropped her) into the hole. And then the bus with the steps, they have to carry me twice from the platform to the bus and then up (the stairs) again. It is so difficult. What if the one on the bus platform is a woman, like an old woman, she is too weak to carry me! Thank God there were many people to help me this time. Can you imagine me doing that by myself? I cannot do that by myself. I can't go anywhere by bus.

Laura: So you can't go anywhere by bus yourself?

Alimenia: No. It is not accessible at all. Only the new bus is accessible because there are seats for us.

Laura: More space?

Alimenia: More space, but the driver, you know. He drives…he knows there is me, people like me, cannot do anything if something happens and still he is driving that way.

Laura: Fast?

Alimenia: FAST and just fast stops. The man on the platform said that almost all the driver do like that. They don't care about stopping close to the platform either. Some may get closer, but it is still too far away.

Laura: Are more people are willing to help you if you ask?

Alimenia: Yes, of course, if I ask. If I ask. When I was younger, we don't have to ask. Like the man from France, remember? The one who sat beside me (traveler on the bus)? He got up and gave his seat to a lady because there were no seats left. It used to be that every man would be that way, but now, you see. They pretend not to see them, so they don't have to get up.

Laura: And they act that way towards people with diff-abilities as well?

Alimenia: Of course! Sometimes they take my place (on the bus). When I went with my sister to get here, we rode the bus. Someone on the bus put all her stuff in my place, on the wheelchair place. Then I said, 'excuse me; this is my place' and she said, you can sit over there. I don't want to move my stuff. There is a sign you know. But then because I complain about her stuff, she gets mad at me. I should not ask her to move her stuff.

Laura: So, it's rude for you to point out that her stuff is on your spot on the bus?

Alimenia: Yeah, but I don't care. That's why I need someone to come with me. If I am alone, someone will smack me or something.

Laura: Smack you?

Alimenia: Yes, that's why I need someone to go with me. If I bring someone, they don't have to do anything. Like you, you don't have to do anything, but people are more respectful.

Laura: So, just the fact that I am standing there with you, they won't do anything to you?

Alimenia: Yeah. They won't do anything with you standing there.

Laura: Is it because I'm American, or something else?

Alimenia: No, it's just because someone else is with me. If I talk to the bus man (the attendant who works on the bus), he is more likely to ask the person to move their things if I am with someone, and then they will move them.

Laura: So, you are saying that the passengers are more willing to listen to the bus man than you?

Alimenia: Yes.

Alimenia's reflection on what it was like to ride the bus this day leads back to a discussion I had with Lestari earlier in the week where she defined accessibility as "the ability to move freely and independently throughout the city and public transportation" (Lestari, 2016). Not only was Alimenia unable to access the bus freely and independently, but she also could not access the bus platform freely and independently as it required multiple people to help her get up the ramp and onto the bus. Alimenia's experience riding the bus is not unique as nearly all people with diffabilities have spoken about similar experiences. For many, these negative experiences have caused them to refrain from using the bus as they are afraid they will not only be hurt from trying to utilizing the bus, but fear being harmed by other people.

In response to why buses and bus stops are still inaccessible despite the ramp comes from Jaka Ahmad, the first blind member on the Jakarta Transportation Council. Ahmad claims that limited accessibility to public transportation is due to the government's belief that people with diffabilities are a small minority within the country. Therefore, spending large amounts of money revamping public buildings and transportation in a country that is still economically struggling is not worth the cost (Rachman and Haryanto, 2012). Therefore, the government's belief that the number of people with diffabilities is low in comparison to the rest of the population and thus not economically reasonable to make all public places accessible for people with diffabilities around the country becomes a self-fulfilling prophecy. This self-fulfilling prophecy becomes a reality as the lack of accessibility discourages people with diffabilities from using public transportation which results in a low number of people with diffabilities being recorded as using public transportation and thus not worthy of the time and money to make stations and buses more accessible.

In response to many people believing that the Transportation Ministry does not care to make public transportation more accessible for people with diff-abilities, the Ministry made public statement stating that they are fully committed to ensuring all public transportation is accessible to everyone. A spokesman for the Ministry, Bambang Ervan, even stated that the government continues to pass legislation for air and rail transport that ensures greater accessibility for people with diff-abilities (Rachman and Haryanto, 2012). Ervan was even quoted saying that the Ministry "monitor[s] and receive[s] reports on whether each [transportation] institution is applying the laws"

(Rachman and Haryanto, 2012, para 23).

Aware of this statement, both Alimenia and Lestari argue, "How are we supposed to report the problem when we do not have access to public transportation to take us to the building where they take reports?" (Alimenia and Lestari, 2016) Also, "If we do make it to the building to make a report, the treat us like we are beggars and tell us to wait in a particular room, and someone will give us money. They do not take the time to listen to us explain why we are there in the first place. They just make assumptions and shrug us off" (Alimenia, 2016). The unwillingness to listen to and see people with diff-abilities as fully human is a continuing problem in Jogja.

Furthermore, and just as important as the infrastructural violence occurring here, is to point out was the socio-spatial exclusion Alimenia described feeling when on the bus. After asked to share her experiences riding the bus, it was not the infrastructure that was salient with Alimenia, but rather the socio-spatial treatment she experiences from other people that contribute to her feelings of not being welcome in public. The fact that Alimenia felt as though people are more willing to show respect to the bus driver or a person who appears to be able-bodied than her is telling and reflects the shift in the perception and treatment of people with diffabilities in Indonesia described in chapter four. The need for Alimenia to spend her time talking about the treatment from others leads me to believe that the social marginalization has a profound effect on one's emotional state as a person with a diffability.

Traveling by Train from Jogja to Solo

Once Alimenia and I finished our discussion on her experiences riding the bus to the market, the three of us made our way to the train station for our hour-long trip to Solo. Once we arrived at the train station, I was surprised to see that each train platform had a ramp, giving the initial impression that the train station provides the accessibility that the people with diffabilities had wished for. However, as we made our way to the platform our train would be arriving at, it was quickly realized that the ramps, though in existence, were much like the bus stop ramp, far too steep for someone in a wheelchair to ascend without help.

Most largescale transportation systems in Indonesia require people with diffabilities to notify transportation officials about their diffability before being allowed to board the transportation they are using. This notification is the same for trains, so once arrived, Alimenia let the ticket master know she was in need of assistance to board the train upon arrival. Afterwards, the three of us made our way over to some of the seats that are provided for waiting passengers. As we sit down, we make small talk as we wait for our train for about 30 minutes. Once our train (train 2) arrived, a flurry of four security guards came out from their office waving their hands and blowing their whistles as they walked in our direction.

Without hesitation, the guards grabbed the back of Alimenia's wheelchair and quickly pushed it over to our train. Confused as to why so many guards came to assist Alimenia up the ramp, I realized that the platform we were now on did not meet up with the side of the train. As a result, there was around an 18" gap between the platform and

train, making it completely inaccessible for Alimenia's wheelchair (see image 8).

Therefore, Alimenia need three of these guards to help her over the gap and onto the train

while the fourth guard talked to the train attendant to ensure Alimenia was welcomed on

the train.

Figure 7:
Entering the Train

Once on the train, it was easy to see that it was a commuter train in that it was set

up with two long hard benches on either side of the car. Much like the bus, this left no

room for Alimenia and her wheelchair to sit safely, so she remained in the aisle way,

holding onto the passenger seat for security.

As the train began to depart the station and people continued finding a place to sit,

Alimenia turned to a young lady and asked if she would be willing to take a picture for

us. The lady agreed, and Alimenia quickly posted the picture on social media's,

FaceBook with the caption "Riding the train from Malioboro to Solo." Within what seemed like minutes, the post generated over 100 "likes" and comments by other people with diffabilities asking Alimenia what the accessibility for the train was like. Within an hour this number jumped to nearly 300 comments and 500 "likes" from people with diffabilities. Many of the comments described Alimenia as brave and how they wish they felt confident enough to venture out into society because feeling as though they were forced to stay home due to the inaccessibility made them feel cut off from the rest of the world. Furthermore, nearly every question involved asking how Alimenia was being treated by those around her as people feared the reaction they would receive by what they considered to be able-bodied people

When we first took this photo, I was ignorant to the impact it would have on the diffability community in Indonesia. To me, I thought it was a friendly picture that would get a few likes on FaceBook. However, it only took minutes for our photo to go nearly viral around Indonesia and was a clear example of how profound the feelings of exclusion are among people with physical diffabilities due to the built environment being inaccessible.

After about an hour of travel, we arrived in Solo only to find that the train station here was not nearly as well designed like the one in Jogja. Here, only trains one and five had platforms that were the trains height. The lack of platform meant that Alimenia had to quickly find people willing to help her get off the train, which was about three feet off the ground.

Figure 8:
Height Relevance of the Train and Ground

Figure 9:
Getting off the Train

A little shook up from the fear of being dropped when being carried off the train, Alimenia immediately approached a security office at the station and asked, "why there no platforms for all the trains?" (Alimenia, 2016). The guard's reply was simple, "It costs too much money to build a platform for every train. Technically we have two, so that means we are following the law and no one ever comes and checks, so why build them if we don't have to" (Solo Station Guard, 2016). Though shocking, Alimenia insured me that this guard's response was one she receives on a regular basis when asking questions about accessibility.

Once out of the train station, we decided to walk around before hailing a cab and going to lunch. As we made our way out of the station, we quickly discovered that Alimenia could not exit the station with everyone who was on foot as the pedestrian exit

was not only too narrow for her wheelchair to pass through, but the walkway was

obstructed by two cement blocks that one had to walk over (see image 11). As a result,

Alimenia had to get in line with the taxis, vans, and motorbikes leaving the station to pass

through an exit, thus putting her in danger of not being seen and hit by a vehicle.

Figure 10:
Barriers in Pedestrian Walkway

After finally exiting the station and taking a quick walk around Solo, we got a taxi

and decided on where to go for lunch. Every restaurant we stopped at has stairs leading

up to the front door, making yet again an inaccessible entrance to a public place we had

visited this day. Due to the stairs and my inability to help Alimenia up the stairs, she had

to ask and tip our taxi driver for help entering the restaurant. Once in the restaurant,

which was crowded and had numerous rectangle tables lining the floor it was easy to see,

none of the tables were designed to fit a wheelchair at them. Though the staff was quick

to suggest we eat at another restaurant, Alimenia insisted they make room for her as we were going to be eating there.

As we ordered and my daughter and I began eating the meals recommended by Alimenia, I noticed she was not eating or drinking at all. I found this to be odd considering it was a typical hot and humid day and we had been out walking around and riding public transportation since eight that morning. I thought to myself; she has to be at least thirst for some water. When I questioned Alimenia about her lack of eating and drinking, she explained to me that the only place that had an accessible bathroom in Solo was the mall. Since the mall was far from where we were, she thought it was best just not to eat or drink till she returned home. At this moment, Alimenia was quick to point out my ignorance to her situation as a woman who uses a wheelchair in Indonesia and she was right in doing so.

I was faced with the fact that regardless of my own physical diffability, my experiences and Alimenia's experiences of diffablement will never be the same. Though I struggled on a daily basis to navigate the built landscape safely while in Indonesia, I was not excluded from the very basic and social behavior as any other able-bodied person could, which includes the simple task of eating, drinking, and using a public bathroom. The realization that Alimenia was forced to refrain from eating and drink in public due to having no ability to use the bathroom hit me hard. Something that seemed so basic and something I had never had to take into consideration before was something that Alimenia had to constantly think about and then decide if she could eat or drink out in public.

Alimenia's inability to use public bathrooms was a clear example of how the built environment leads to experiences of socio-spatial exclusion as so many people with physical diffabilities are unable to access restrooms when out in public. Not being able to engage in social activities such as eating and drinking in public due to the inability to access the restrooms often force people to either remain home or only venture out into public for very short periods of time to gather necessary items.

This experience of Alimenia not being able to use the restroom caused me to reflect on my experience during the day deeply and how I lived within my own an ablest habitus. This habitus was formed and then recreated through my unconscious thought and actions in regard to my ignorance to why Alimenia was not eating or drinking while in Solo. According to Bourdieu (1990), habitus is "…embodied history, internalized as second nature and so forgotten as history…" (p. 56) "and its positon is already absorbed and deeply adhered to within every individual or source of agency (Thohari, 2013, p. 114).

Within both my and Alimenia's experience as people living with diffabilities, we can see how our experiences, social backgrounds, socio-economic status, and nationalities have shaped our differing perceptions and practices in regard to diffability. Through my own experiences here in Indonesia, it is easier for me understand how different discourses about diffability continues to develope habitus' that are in constant competition with one another in regard to accessibility throughout the city, which I go further into in the following chapter.

Once arriving back in Jogja, the three of us wondered around Malioboro

Marketplace as Alimenia wanted to show me around for a few hours and had not been the marketplace in a few years. Though exhausted from our trip to Solo, I agreed and off we went into the crowded streets of Malioboro. What follows next is a conversation that followed that trip and directly points directly to the everyday socio-spatial exclusion people with diffabilities face in Jogja.

Alimenia**:** I've been here for three years (Jogja) and the first time I came here almost all the sellers ask why are you here? To buy or sell?

Laura: Why did they ask if you were there to buy or sell? They never asked me that question.

Alimenia: Because it is unusual for someone in a wheelchair to go to Malioboro to buy. Some people come to Malioboro with their brother or mother, so they don't ask them. But I went alone, and that was unusual, so they thought I was there to beg. So they looked at me like I was an alien and made me feel like one too. They looked at me up, down, up, down, how I move. They follow me everywhere with their eyes, head, and body.

Laura: Did people ever help you (in the past) like they did today?

Alimenia: Yes. They would still help me.

Laura: Did they help you because they wanted to help you, or because they were curious about you?

Alimenia: Out of curiosity and pity. Like the man today who said, 'it's okay I can push you' even though I said I can do it by myself. At first, I thought I have to pay him but the second thought I will teach him a bad lesson if I pay him because he will lose his empathy by doing it that way.

Laura: Because now all of a sudden, it's going to be I'm helping the diff-abled for money?

Alimenia: Yeah, and I don't want to do that. So I decided to just say 'thank you very much.' That is all. If I come there again, and I see him again, I will say, 'hello, thank you.' That is what I do. I try to teach people about handicapped people. Then because I've made friends with them, they will help me in the future.

Laura: That's one way to do it. So how did you feel about the accessibility around Malioboro?

Alimenia: Compared to three years ago (the last time Alimenia had been to Malioboro) not much has changed. The ramps are still steep, and the market is still crowded. Oh, I

have a good example. You know when there is a hallway, it's so narrow I can hardly pass because of all the people in a little place. So usually I just push the people and say 'excuse me, excuse me!' I don't care. They are in front of me, so if I push forward, the wheelchair will touch them, and they will look back and see me and move. This is why I am told I should not go to Malioboro. There are too many people. But I don't care about that. I still go.

Laura: The crowds cause people with diff-abilities to not go to Malioboro?

Alimenia: Yes. It is too difficult for them. They don't want to act like me. They don't want to have a debate or protest or complain. They don't want to do that. I do, I don't care. But I try to say it nicely and humorously. I tell myself it is something fun.

Laura: Does that mean you enjoyed your day in Malioboro?

Alimenia: Oh yes. I love to go places. Sometimes I ask God why he gave me this kind of spirit because I love to travel, but I feel like I cannot travel everywhere easily because of my wheelchair.

Laura: Right. So it's like your personality, and your body don't agree.

Alimenia: Yes! They don't agree. The first time I lost my passion and did not go out for a day, I felt sick from not going out. I must go out. I can only go to the mall and Malioboro.

When people say, 'you always go to the mall, why you always go to the mall' I tell them because it is the safest place for me.

Laura: Why is the mall the safest place for you?

Alimenia: Because at the mall there are so many security, they (the people) won't do anything to me because they think they will get in trouble from security.

Laura: What kinds of things do people do?

Alimenia: Rob me. They will snatch my purse or my bag. If I went to Malioboro, I use long strap purses so I can wrap it around myself or my wheelchair so if someone tried to snatch my purse, it is not so easy. I have to think about all of my situation if I go to public places.

Laura: So you feel you have to think through your safety when going to public places more than the average person?

Alimenia: Yes. If I go alone, I usually wear my jacket, so people don't see my necklace.

Laura: Are you afraid someone will take your necklace if you are not with somebody?

Alimenia: Ya or they will kill me.

Laura: Over your necklace?

Alimenia: Yeah!

Laura: Because you are diff-abled?

Alimenia: Oh no. This is for anybody. This is why I wear my jacket so they can't see it. It protects me. People like me have to be smart. We have to try and hide our condition.

Laura: Because people see it as a sign of vulnerability and weakness and take advantage.

Alimenia: Yeah. So we have to be smart and tricky to handle the situation if we want to have the same fun. Like if I want to watch a movie, it is not accessible at all.

My excursions with Alimenia did not begin and end here with our trip to Solo but continued for the entire week. During this time, I not only was able to see how differing discourses and experiences shaped people's perceptions about diffabilities and the people living with them but also was witness to the overwhelming need Alimenia had for people's help when moving to and through the city. This constant need for assistance required constant physical touch from strangers. It was as if being a person with a physical diffability meant constant experiences with forced intimacy in exchange for

access to public places, such as Alimenia's experience of having her wheelchair pushed by a man regardless of telling him she was capable of doing it on her own.

Forced intimacy comes in many forms. It can be anything from being expected to open up and share personal parts of one self to receive basic access, down to the forced physical intimacy which is that of needing physical help that requires the physical placing of one's hands on another for the sole purpose of accessing a place that is meant to be both public and social. "Forced intimacy is a cornerstone of how ableism functions in an able-bodied supremacist world" (Mingus, 2017, para 3) where human interaction becomes a logistical exchange. Even within my research, I am skeptical as to whether or not my work presented here falls along the lines of forced intimacy. I question this because the people I worked so closely felt as if they were expected to "strip down," show all their cards and become vulnerable with me regardless if they want to or not order to get the basic access they need to survive (Mingus, 2017). Perhaps the fact that those in my work came to me hoping to be part of this work on infrastructural violence and socio-spatial exclusion means as though they consented to being vulnerable with me by sharing intimate details about their lives and bodies, forced intimacy is still called into question as they needed to reveal these personal details to a broader audience (my readers) in order to make a stand against the everyday injustices they experience as a person with a diffability.

CHAPTER 7: CHALLENGING LEGACIES OF ISOLATION AND STIGMA

Over the course of my research I was invited to listen to an untold number of personal stories that attested to the feelings of struggle, exclusion, and oppression. I was also encouraged to join in on excursions throughout the city of Jogja to experience firsthand the feelings shared in these stories. The majority of the stories and experiences shared with me indicate feelings of powerlessness that surrounds their daily lives. While those I worked with shared stories of struggle, exclusion, and oppression, they also went on to recount stories of past triumphs and strengths and dreams of their futures.

This chapter explores these accounts as individuals with diffabilities in Jogja describe experiences of new forms of socio-spatial exclusion through globalization and political activism as they demand a more inclusive society. Throughout the chapter I discuss how community groups, diffability agencies, and individuals with diffabilities have taken up the important role in contesting their discrimination through the promotion of diffability rights in the face of absent local and national efforts. I also intend to highlight the triumphs these groups have reached due to their shared experience of marginalization which has banded them together to push back against both cultural and practical aspects of their oppression as they argue that accessibility is a fundamental prerequisite to the utilization of their "right to a city" (Mitchell, 2003).

Fighting for an Inclusive Space

If there is a place in this world where the Central European political term "nothing about us without us" vibrantly plays out, it is in Jogja city. I cannot emphasize enough the importance of people with diffabilities being the pillar of change when it comes to pushing for their rights. Jogja is a prime example of how people who face a collective marginalization have come together and have created an immense movement that has begun to develop the much-needed change throughout the country when it comes to the inclusivity of people with diffabilities. Here, the ideology and perception of what diffability and accessibility is largely based on the social model of disability (see chapter three).

Based on the understanding that diffability is caused by social norms and not a pathological issue, diffability activists who are a part of, but not limited to: SIGAB, Dria Manunggal, the Center for Universal Design, Diffability at UGM, United Cerebral Palsy, Indonesia, and Sentra Advokasi Perempuan Difable Dan Anak (Advocacy Center for Diff-abled Women and Children) continuously advocate for the accessibility of people with diffabilities in public places. With the support of international funding these agencies have been a champion in promoting the rights of people with diffabilities throughout Jogja and have been the main driver of many pilot projects such as the Maliobro Project.

Awareness of diffability issues takes comes largely from people with diffabilities and is seen in the form of article and book publishing, public demonstrations and protests, seminars, dialogues, and lobbying the government and policy-makers demanding

accessibility be part of enforced laws. Much of this work has paid off, but slowly as one

can see in chapter six. For example, new buildings are being constructed to be more

inclusive with the use fewer less stairs and more ramps and elevators. Universities such

as UGM, Sanata Dharma University, and the National Islamic University of Yogyakarta

have made further renovations in the attempts to accommodate a growing body of

students with various diffabilities and finally the signing of Surat Nomar

B/4965/XII/2008/ by all chiefs of police in Jogja which allows people with diffabilities to

hold a driver's license. This license allows people with diffabilities to drive modified

motorbikes, such as the one driven by Lestari, which in the words of Lestari, "gives

people with diffabilities the freedom to access the city on their own terms" (Lestari,

2016).

Figure 11*:*
Modified Motorbike

With this new law allowing people with diffabilities to drive, perhaps the most

unique and accessible mode of public transportation was created by a man that goes by the name of Triyono and was designed for people with diffabilities. Difa City Tour and Transport was launched in May 2015, and each and every employee and customer are people with diffabilities. Each of the motorbikes is modified, like the one pictured above to accommodate a person's wheelchair. According to Triyono, his modified taxi company remains the only one in the world that hires only people with diffabilities, which allows them to hold a job and earn a steady income as 90% of the taxi fare goes to the driver (Indonesia's disabled motorbike taxi service, 2017). Though Triyono states that the taxi service is designed for people with diffabilities, the drivers also provide rides for able-bodied people as a way of not only earning an income, but as a form of showing pride in what they do and the capability of doing it.

Before the creation of Difa City Tour and Transport, one of most prominent accessibility pilot projects to take off in Jogja is that of the *Malioboro Pilot Project* initiated in 1999 by the Department of Architecture, Faculty of Engineering at Gadjah Mada University. This pilot project was the instillation of a large yellow brail line across three kilometers (9842.52 feet) of the marketplace. It is considered to be one of the first projects to be implemented through the city concerning accessibility of people with diffabilities and has had promising results. However, today the pilot project continues to face both technical and social problems without much resolve. One of the biggest problems stemming from this project is the lack of people's awareness about what the raised yellow line is intended for, which is something recognized within my work here in Jogja.

My interest in this project began during a discussion with Lestari about what measures have been taken to address inclusivity of people with diffabilities in Jogja. As a result, I developed a survey for people at Malioboro Marketplace which included questions about the yellow brail line. Alimenia agreed to accompany me as both a companion and translator for those who did not read or speak English. Finding people willing to take my survey was relatively easy as mentioned previously, Jogja is an academic city so people were more than willing to engage with me.

One of the first questions I asked people who agreed to take my survey was "do you know what the yellow stripe going down Malioboro is for?" followed by "Do you think it is easy to get around Jogja for people with diffabilities? Out of the 20 people I talked to, six said they knew what the yellow strip was for and 14 said they did not. Furthermore, 16 of the 20 people said they believed it was easy for people with diffabilities to move around and only four said it was not. These answers point to the lack of social awareness about the need of accessibility of people with diffabilities.

What was even more interesting outside of these answers, which were more or less expected was two conversations I had with three different people: two college age girls and one male vendor. When I approached the two young college girls and they agreed to participate in my survey, I asked how often they come to this marketplace. Both the girls responded in an embarrassed giggle with "every day." Afterwards, I proceeded to ask my question about the yellow line. Both of their immediate responses were, "what yellow line?" A little surprised, my initial reaction was to look down at our feet as we were standing on the very yellow line I was talking about. Both girl's eyes followed mine

down to the ground and immediately began giggling and said, "we've never seen this before, even with all the times we have come here."

Afterwards, Alimenia sat with them and discussed the yellow line's purpose, which is to help people who are blind navigate their way through the marketplace safely as the brail gives them a path to follow. Furthermore, the yellow line indicates the need for vendors to place their stands far enough back that there is enough room between them and the street for wheelchairs to pass through comfortably. At the end of the conversation, the two girls agreed to go on and educate their friends about the importance of accessibility and the purpose of the yellow line found along the three kilometers of the marketplace.

The next person I talked to was an older gentleman who was an everyday vendor in the marketplace. After the usual introduction and agreeance to be a part of my survey, I asked the man about the yellow line. Much to my surprise he answered, "yes, I do know what the yellow line is for." Intrigued, I asked him to tell me what it represents. The man said, "it tells us vendors where we are allowed to park our carts and stand. It represents that we cannot sell past this point on the sidewalk. That is why we all get here so early so we can place our things as close to the line as possible so we are the first to be seen by people."

Figure 13:
Blind Guide Block

Upon hearing this answer, Alimenia began to immediately school this man on the actual intention of this line. With a look of surprise and frustration, the man immediately moved his cart off the yellow line by a few feet and began instructing other vendors around him to do the same. The man then returned after reorganizing his section of the marketplace saying "I had no idea that is what this yellow line was for. If we vendors knew this, we would not place our things here. The man who is in charge of the vendors here told us it is the line we could not sell our product past, not that it was for people with diffabilities. If we knew that, we would happily not place our carts and stands here." This man's passionate response to being told the true purpose of the line goes to show the lack of awareness most Javanese people have towards inclusive and accessible projects being implemented throughout the city. With more awareness, I believe there is the potential for the overall population of Jogja to be open to a more accessible environment.

Struggles and Strengths Between Diffability Agencies

In a conversation with a man who works for the organization, Sentra Advokasi Perempuan Difable Dan Anak (Advocacy Center for Diff-abled Women and Children) we discussed the importance of diffability organizations in Jogja, their purpose, and their power together as well as struggles against each other. In recent years, numerous agencies, including the more prominent ones listed above, have been created in response to the grown diffabilities grassroots movement occurring in Jogja.

Each organization has taken on a cause that the diffability community has expressed and then tackle the issue on most occasions in one of five ways: (1) Persuasion. For these agencies, persuasion takes the form of going out and talking with people in the hopes of convincing their listener that people with diffabilities are equal and deserve equal access to public and social areas of the city. (2) Parades and performances that occur on special days in Indonesia such as Independence Day and Disability Day and consists of carnivals, pantomimes, theater, music all in hopes of making others aware of not only the issues faced by people with diffabilities, but that they are just like anyone else and deserve equal access to public arenas. (3) Advocacy. In Jogja, diffability advocacy looks not only like the activities listed above, but includes protesting against cases of discrimination against people with diffabilities. (4) The publishing of bulletins, magazines, blogs, movies, and documentaries about what diffability is and the rights of people with diffabilities. Lastly (5), organizing and empowerment, which consists of working with people with diffabilities to become advocates for themselves and join ongoing movements and organizations.

In fact, one of the largest demonstrations that took place in Jogja that ultimately launched the movement into full force was that of the general election of 2004 when a blind man was prevented from running due solely to his inability to see. Almost immediately, diffability activists took to the streets protesting this decision. Agencies began organizing seminars and public discussions on school campuses about diffabilities and diffability related issues (Thohari, 2013). In one instance, there was a publication in one of the largest newspapers that read: "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, 2007 as cited in Thohari, 2013). In short, this election launched the diffability rights movement into full force.

Since then, community engagement and the encouragement of these agencies in getting people with diffabilities to empower themselves has not slowed down. More and more agencies are popping up throughout Jogja, however, with the more agencies being established, the more internal conflicts between them are on the rise in regard to obtaining resources, achieving transparency, and selecting leaders. Though these issues have created some fragmentation between the organizations, they have created a stronger effect in terms of development of paradigms. Furthermore, even with the disunity between them, these organizations have been successful in creating positive change within their communities.

Sendangtirto Village is one of most cited success stories of the diffabilities movement to create a holistic change in terms of inclusiveness for those living with

diffabilities in Jogja. In 2014, SIGAB and village leaders got together and hosted an

"Inclusion Forum" with people in the village. The purpose of this forum was to discuss

diffability related issues in the family and community realms (The Asia Foundation,

2015). Throughout the open discussions, SIGAB members began noticing families

beginning to stand behind family members with diffabilities and speaking up and

promoting the importance of an accessible social and built environment. It is said that

Sendangtirto Village has even stepped forward with the desire to build an accessible

Public Health Center, which is an example of how important it is for an entire community

to be educated on and aware of diffability related issues facing the people of Jogja.

As we can see, despite some internal struggles among diffability agencies in

Jogja, they have been able to come together to create one large network with the goal of

creating a more inclusive society where people with diffabilities can access both social

and public realms while also maintaining their smaller focus on different areas of

diffability rights. These agencies and the people who operate within them have come to

create their own habitus group through a shared oppression and desire to create a more

welcoming environment for themselves and others.

CHAPTER 8: CONCLUSION

There comes a point where the recognition of the value and contribution that people with diff-abilities can make when they are invited to participate within their community, economy, and government needs to be recognized and accepted. This parallel world of those with diffabilities and without in Jogja is one I strived to understand through this research. Created through my own struggles as a person with a physical diffability, this thesis attempted to illustrate the significance of socio-spatial exclusion and infrastructural violence faced by those with diffabilities in Jogja. Through the creation of friendships and the formation of trust within them, I came to understand how diffability is a form of violence where the mere form of a body elicits discrimination, suspicion, and fear as they fight for the right to make use of public life.

In the conclusion of this thesis, I ask cannot help but to ask myself, "How can I contribute to ending both structural and symbolic violence towards people with diffabilities in both Indonesia as well as my own community?" Though the answer seems simple, make society both physical and social more accessible, but as Bourgois and Scheper-Hughes (2004) remind us, "the social and cultural dimensions of violence are what give violence its power and meaning" (p. 1). To address the infrastructural violence faced by people with diffabilities, one must first start on the level of society and history has taught us it takes generations along the social line for full change to occur.

When I first began this work, little did I know how much it would change my life.

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The last few months to which I engaged in this research has not only given me a new-found sense of identity as a person with a diffability, but has thrust me into a life that has brought me closer to the lives of those I had originally distanced myself from. This ethnographic study of the marginalization and oppression of those living with a diffability has sought to bring their stories to the forefront as it captures their daily life as they navigate the spaces and places of Jogja city and challenge the cultural perceptions placed upon them in the form of pity and fear.

Though my research for this thesis has ended, my engagement with the diffability community has just begun as I continue to learn from members of the diffability community both in Indonesia as well as the United States. I am not under the assumption that this research will have the same impact on the academic or policymaking community as it has me, but I hope that it will offer the ongoing conversation about diffability rights a new and fresh perspective from an environment where people with diffabilities are taking an active stand against oppressive structures as they work towards building and co-creating an inclusive society for all members.

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BIOGRAPHY

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