Chapter 7

Gender, Disability, and Access to Health Care in Indonesia: Perspectives from Global Disability Studies

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Introduction

Disability is a global health crisis. About 15% of the world's population or approximately one billion people are living with a disability—usually defined as a motor, sensory, speech, learning, developmental, or intellectual impairment or chronic illness. The World Health Organization (WHO) and United Nations (UN) estimate that between 110 and 190 million people live with what they define as "severe disabilities" [1]. If we add mental illnesses and autism to the list of disabilities, the number rises. A 2011 WHO report states that "Across the globe 450 million people suffer from a mental or behavioral disorder. The estimate is that one in five persons will suffer from a mental illness in a given year" [2]. The WHO predicts that "depression will be the number one global burden of disease by 2030, surpassing heart disease and cancer, and [it is] anticipated to be the number two burden by 2020" [2].

Disability or mental illness can affect anyone, anytime. We are all likely to encounter disability at some point during our lives, whether it is through our families, our jobs, our recreational activities, or through our own bodies. Approximately 85% of disability is acquired throughout our lifetime. This means that only 15% of disabled people are born with their disabilities [3]. Disabilities are usually caused by unsanitary, unhealthy, overcrowded living conditions, malnutrition, war, environmental hazards, disease, poverty, accidents, and childbirth, among other social factors.

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People in the developing world and women are more likely to experience disability; 80% of people with disabilities live in developing countries. Both the UN and the WHO have found that there is a higher representation of women among the world's disabled population [1]. The disparity in occurrence of disability between women and men is the product of a complex mix of factors. However, it is clear that one of the root causes of a higher rate of disability among girls and women is the general devaluing of girls and women in society.

In this chapter, we will use a close reading of secondary literature and a collection of open-ended interviews of disabled Indonesian women conducted in part by co-author Hanita Djaya to analyze the social, economic, and structural barriers women and girls with disabilities face when attempting to access healthcare in Indonesia. We will use an interdisciplinary global disability studies approach that engages with the ways in which social class or caste, gender, ethnicity, language, and religion affect the lived experiences of girls and women in South and East Asia, and more specifically in Indonesia. It is our contention that a careful qualitative analysis of the lived experiences of disabled people is an important way to build what Rapp and Ginsburg have called the "social fund of knowledge" concerning disability and disabled people [4].

A Global Disability Studies Approach [1]

Before we begin our discussion of disabled women and girls in Indonesia, we will provide a sketch of what it means to take a global disability studies approach to considering disabled people's access to healthcare. Disability studies is an interdisciplinary academic endeavor that analyzes disability and the lived experiences of people with disabilities from the perspective of the humanities, social sciences, and arts. Disability studies has a tenuous, often critical relationship with the medical and applied fields (such as rehabilitation science or other health related fields).

One of the basic tenets held by disability studies researchers is that "disability" extends beyond individual bodies. Disability is not merely something that an individual has (I have cerebral palsy), or is (I am a paraplegic). Disability is socially created by built environments, cultures, and social norms that devalue, stigmatize, segregate, or discriminate against people who are considered "abnormal." Disability studies scholars have labeled their focus on the interactions between disabled people and the world around them the *social model* of disability, which they define in opposition to an older, well-entrenched *medical model* of disability that sees it in more negative and individualizing terms. The medical model defines disability as a deficit or defect that must be fixed, cured, or eliminated in order for an individual to function "normally" in society. The social model of disability does not view disability in the same way.

The Social Model of Disability

The social (also called the socio-political) model of disability originated among disability rights activists in the United Kingdom in the early 1970s. Its primary purpose was to separate the conceptualization of disability from that of impairment; to say that disability was something that was socially created, while impairment was merely a biological fact with no cultural values attached to it.

Under the social model, what became disabling for people was not their inability to walk, see, or hear (for example), but rather the inaccessibility of a physical, social, and cultural environment that remained hostile to their presence in it. As the British Union for the Physically Impaired Against Segregation (UPIAS) explained, disability is "a form of [socially created] disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments" [5]. Put simply, the social model of disability makes a critical distinction between impairment (body) and disability (society). It roots disabled people's limitations in societal barriers that disable them, not in any individual embodied deficit. Disability studies scholars refer to this system of exclusion as "ableism." They argue that ableism and ableist attitudes are present in all societies that are built by and for nondisabled people [6, 7].

The social model of disability redefines disability as something created in the social world, and not through biology (or genes or neurochemistry). This new way of thinking about disability has enabled scholars (and activists and artists) to move disabled people away from their historical place in society as individuals in need of medical, rehabilitation, welfare, and other services and interventions to that of an oppressed social minority in need of recognition of its civil and human rights. By discarding the notion that disability is negative and rooted in the individual, and by thinking critically about the power of various social arrangements to disable, social model theorists have been able to develop a powerful understanding of what it means to live differently in the world. Part of the success of the social model derives from its ability to expand the definition of disability to include a broad range of impairments, illnesses, and conditions, and to show that disability will touch everyone at some point in their life. The tremendous diversity among the world's disabled population and the broad range of experiences we all have with disability have been a source of empowerment for disability rights activists and academics alike.

Global Disability Studies

One critique of the social model that has emerged within disability studies comes from scholars interested in global disability studies. Disability studies scholars working on non-Western topics and those working outside of the Western English-speaking world (alternatively referred to as *the global North*) are finding that disability studies theories that are dominant in the West or global North, including the social model of disability, are often ineffective, or in some cases only partially effective, in helping to explain the lived experiences of disabled people in other parts of the world (referred to as *the global South*). Global disability studies theorists make strong arguments for avoiding the uncritical exportation of global North disability studies theories to the global South, and, instead, argue for situating analyses of the lived experiences of disabled people in their own local cultural and historical contexts, social relations, and governing structures, as well as larger international political and economic systems. Rather than dismiss global North disability studies, global South scholars encourage collaborative and constructive dialogue between North and South, which they argue will build stronger disability studies analyses and more powerful disability politics in both parts of the world [8]. It is with this view of global disability studies and its critique of the British and North American social model of disability in mind that we turn to our discussion of disabled women and girls in Indonesia.

Disability and Gender in Indonesia

Indonesia is a South East Asian island nation with a population of about 260 million (in 2016) people. It is ethnically and linguistically diverse. More than half, almost 60%, of Indonesians live on the island of Java, the most populous island in the world and the home of Jakarta, Indonesia's capital. The World Bank considers Indonesia a "lower-middle income" country with a Gross Domestic Product (GDP) of about $932 billion US dollars annually. By comparison, Canada, India, and the United Kingdom have GDPs that range from 1.5 to $2.6 trillion US dollars annually. About 10% or one out of every 10 Indonesians live in poverty. Until recently and relative to other countries, Indonesia spent very little on publicly funded healthcare services, only about 3.1% of its 2013 GDP.[1] The global average for publicly funded healthcare services is about 10% of GDP. Until 2014, most Indonesians relied primarily on a privatized "out-of-pocket" system to fund healthcare, where individuals paid directly for the healthcare they received [1, p. 13]. Although both systems were regulated with the intent of providing adequate and accessible healthcare to all Indonesians, the reality was that great disparities existed among different segments of the population, with poor, rural, and disabled people suffering the most severe

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[1] Poor Indonesians used a mix of regional and national public health insurance schemes. Although coverage varied and it was means tested, most beneficiaries received a comprehensive package that included inpatient and outpatient care, as well as generic prescriptions, with no premium payments or copayments upon visiting the doctor. 76.4 million people used Indonesia's national public health insurance program known as *Jamkesmas* in 2009. For more information on health insurance see: Adioetomo, Sri Moertiningsih, Daniel Mont and Irwanto. 2014. *Persons with Disabilities in Indonesia: Empirical Facts and Implications for Social Protection Policies.* Jakarta: Demographic Institute, Faculty of Economics, University of Indonesia. pp.107–117.

inequities. In 2014, the Indonesian government implemented a national healthcare program called the Social Security Administrator for Health (BPJS), providing "broad-ranging" coverage to all of its citizens, including those experiencing mental health problems and those living on the autism spectrum [1, p. 143], [9, pp. 3–19]. Even within this system, however, disabled people continue to face significant challenges and constraints.[2]

Although Indonesia is showing signs of improvement with respect to disability and disabled people, negative attitudes continue to persist and they remain gendered, especially within poor and rural communities. In general, disability and disabled people are something to be pitied in Indonesia. Disability is considered "shameful" and "dirty" [9]. Many parents believe that "if my child is handicapped, he/she cannot live a normal life" [9]. If a married woman becomes disabled, her husband can legally divorce her [9, p. 3.76]. Although the language is changing—the official word for disability is "disabilitas"—words like "cacat" (incomplete, disfigured, defect) and "Orang gila" (crazy person) can still be heard in public [9, p. 3.3]. Disabled women and girls are statistically more likely to experience violence, abuse, discrimination, and isolation in Indonesia. Studies have shown that some disabled people have internalized these negative attitudes and report feelings of low self-confidence and low self-esteem [9]. There is, however, a growing group of disabled people and their allies, who will be discussed in more detail below, who are fighting to change these attitudes. This social and economic context is critical for understanding disability and gender in Indonesia.

The Indonesian Ministry of Health estimates that approximately 11% of the population, or 27 million people are living with "at least one moderate to severe disability" [1, p. 12]. It is likely that the number of disabled people living in Indonesia is higher than the official count would indicate. Most reports only consider "vision, hearing, mobility or climbing stairs, concentration, cognition, and self-care" when tabulating disability [1, p. 13]. Behavioral disorders such as those related to autism spectrum disorders and mental illnesses go relatively unrecognized in most studies. Social and cultural stigmas, which will be discussed in more detail below, also mean that many disabled people and their families will hide disability from public view. That most of the Indonesian population is rural and 10% live in poverty, also means that in most cases disability will go unmarked and untreated. Additionally, some studies indicate that disabled women (and presumably girls) outnumber disabled men and boys by about 3:1. Because women and girls, specifically disabled women and girls, are not valued as highly as men in Indonesian society, the likelihood is

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[2] The Indonesian government has passed a number of laws that directly address access to transportation, education, employment, and healthcare. These laws, however, remain unfulfilled due to a lack of funding and political interest. Disabled people in Indonesia, like disabled people in most countries do not possess significant social or cultural capital that would enable their demands to be heard by politicians and government leaders. For an extensive list of laws see: Japan International Cooperation Agency (JICA). 2015. *Data Collection Survey on Disability and Development in Indonesia Final Report.* (KRI International Corporation, Tekizaitekisho, LLC.) p. 3.10–23.

that their numbers are also underrepresented in official counts. One study has found that only about 10% of disabled children are registered and enrolled in school and that there is “a high possibility that persons with disabilities are not registered as citizens at birth, as mandated by law, and are thus not eligible to receive education, medical, employment, care, and welfare services” [9]. This means that they also go uncounted in national studies.

Recognizing that at least 11% of its population is living with some form of disability, the Indonesian government has implemented measures to ameliorate the conditions under which most of its disabled people live. On 30 March 2007, it signed the UN Convention on the Rights of Persons with Disabilities (CRPD). In 2009, the government issued Undang–Undang No. 36, which one researcher describes as legislation that requires the government “to look after the health of elderly and disabled people by providing an accessible health service, and other facilities, to enable this sector of the population to live independently and productively” [1, p. 12]. The Indonesian government ratified the CRPD in November 2011 [9, p. 1.1]. Officially recognizing the UN CRPD and passing legislation that specifically addresses the needs of disabled people is an important first step. However, as long as public-sector healthcare remains underfunded and Indonesians continue to rely even in part on a “pay-as-you-go” system, the needs and desires of disabled people, especially disabled women and girls will not be met by these largely symbolic efforts toward inclusion. Indonesia is a decentralized island nation, where culture and language, as well as poverty and underdeveloped infrastructure outside of major urban areas prohibit efficient transportation and communication and limit access to healthcare for most Indonesian people, especially disabled women and girls.

Health Related Disparities of Girls and Women with Disabilities in Indonesia

Studies confirm that women with disabilities living in Indonesia have negative experiences when receiving healthcare services, especially if those women live in rural areas [1]. The unequal treatment of disabled women, and in some cases their exclusion from healthcare services are experienced in several important and interrelated areas: (1) inadequate healthcare systems and services, which can include ignorance and inexperience among professionals and staff; (2) stereotyping, stigma, and discrimination concerning the need for access to healthcare, especially reproductive and sexual healthcare; (3) a lack of physical access, which can include inadequate transportation, inaccessible buildings, and inaccessible medical equipment; (4) general attitudinal barriers among the community, which leads to increased segregation and isolation for women with disabilities; (5) a lack of recognition of disabled women’s desires to be considered “normal”; and (6) difficulties creating a positive self-image [1, pp. 112–113].

Although conditions appear to be improving in the years since Indonesia signed the UN CRPD in 2007, disabled women and girls continue to face significant challenges in accessing adequate, affordable, safe, and effective healthcare. Disabled girls and women are more likely to experience violence, sexual assault, and isolation, even within their own families. They often have to travel great distances to access healthcare. Public transportation is unreliable and often inaccessible. In some locations and under some provisions, disabled women are grouped with the elderly in terms of healthcare provision, despite their vastly different needs and concerns. Disabled women of childbearing age—especially those who have already had a child—are more likely than other women to face pressure to undergo sterilization procedures to prevent pregnancy. In general, negative attitudes toward disabled women and girls continue to persist both within healthcare settings and in the community.

Many disabled Indonesian women, like disabled people in other parts of the world, rely on a range of disabled people's organizations (DPOs), non-profit organizations (NPOs), and non-governmental organizations (NGOs) that focus specifically on disability related issues, and in some cases are led by disabled people themselves, to advocate for their rights and provide them with important material support and a sense of community. Disability focused DPOs, NPOs, and NGOs are more active in Indonesia's urban areas. Djaya's interviews confirm that disabled women and girls living in rural areas have a difficult time utilizing these organizations, which are critical in the lives of disabled people who wish to improve their access to education, healthcare, and employment.

While it is not as robust as it is in other countries, like neighboring Japan, for example, Indonesia has a strong and growing disability rights movement that is led at the national level by prominent disabled people's organizations or DPOs. One of the oldest and most active rights-based organizations is the Indonesian Disabled Persons Association (PPDI), which was established in 1989 and is a member of Disabled Peoples International (DPI). The PPDI works closely with relevant governmental ministries to create policy and enact legal changes designed to ensure the rights of all Indonesians living with disabilities. In addition to the PPDI, disabled Indonesians and their allies have also formed the Movement of the Welfare of Deaf Indonesia and the Indonesia Blind Union. The most prominent organization that focuses specifically on issues related to women with disabilities is the Indonesian Association of Women with Disabilities (HWDI).[3]

The HWDI, formerly known as the Indonesian Association of Handicapped Women was established in September 1997 as a socially oriented, rights-based organization for women living with various types of disabilities, including physical, sensory, and mental disabilities, as well as the parents of children with disabilities. The national organization is based in Jakarta. According to one of Djaya's informants, Maria, the HWDI was established to answer to global demands for the

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[3] For a more extensive list of major DPOs in Indonesia see: *Data Collection Survey…* 2015, p. 3.82.

empowerment of women (and girls) with disabilities. Part of the mission of the HWDI is to ensure that the issues of women and girls with disabilities, and gender equality, are not forgotten in the movement for the rights of people with disabilities and also in other women's organizations in Indonesia. While the HWDI does not focus specifically on healthcare related issues, it does focus on promoting physical accessibility and advocating for legislative measures designed to ensure the rights of women and girls with disabilities, which as we have argued has a direct impact on healthcare and health related issues. The HWDI has a keen interest in promoting the reproductive and sexual health of women and in preventing women and girls from becoming the victims of violence and sexual abuse through legislation and other activist means.

The fourth largest country in the world, behind China, India, and the USA, Indonesia has made significant gains in securing the rights of people with disabilities. But significant work remains to be done in the area of changing the general population's attitudes toward disability and the equal acceptance of disabled people in education, employment, and in the provision of healthcare. Negative attitudes toward disability can be seen clearly in oral interviews with disabled women living in Indonesia (Fig. 7.1).

Notes from the Field

In this final section of the essay, we will move from the macro-level, where we provided a large-scale assessment of disability and gender in Indonesia to a closer look at the lives of specific women with disabilities living in various parts of Indonesia. The interviews were conducted by Djaya in 2017 and 2018. It will become evident upon reading these brief excerpts that women's lived experiences confirm many of the arguments presented in this essay, which are further supported by larger-scale demographic and policy studies conducted primarily by NGOs. Because the women interviewed for this essay were self-selected and in most cases are active in the disabled community, the reader will find that some interview subjects present their disabilities and their experiences in a positive way that may not be representative of the larger disabled population living in Indonesia. Some of the women interviewed for this study benefit from a class status that enables them to attend school, usually in mainstream settings, and also attend college or university or receive advanced training in particular employment sectors. Some of these women possess the social and cultural capital as well as the technological skills and access to resources and technology that enable them to succeed. These are benefits that are not readily available to many Indonesian people, especially disabled women and girls and those

Fig. 7.1 Socially created barriers to health equity for girls and women with disabilities in Indonesia. (Source: Nicole Little and Michael Rembis)

people living in rural areas. A study that explores the experiences of a broader range of disabled women and girls, and especially focuses on their access to and utilization of healthcare, is strongly needed in the field of global disability studies. Despite their limitations, however, the following oral interviews contain much-needed insight into the experiences of disabled women in Indonesia.

Anggi (21 Y.O)

Anggi has been deaf since age 3, when a high fever led to her hospitalization and eventually the loss of her hearing. When she was old enough to go to school, her parents applied for her to attend kindergarten, but she was rejected do to her disability. Her parents enrolled her in a “special school” where she was in a class with other deaf children. She remained in that school until she was old enough to attend high school, at which time she entered a mainstream school, where her teachers gave her junior high textbooks instead of high school textbooks because they assumed she could not learn. Anggi remembers that many of her teachers were “nice,” but they were unable to communicate with her because of language barriers. They did not know how to sign and there were not any interpreters for deaf students.

Despite these disadvantages, Anggi was able to succeed. At the time of the interview, she was studying as a freshman in the Makassar Public University, majoring in special education. Anggi claims to experience “no discrimination” in her university education, yet she is forced to attend class without a sign language interpreter, because none is available. The local deaf people’s organization relies upon informal networks of support like friends and family to provide interpreting for people. In class, Anggi counts on her friends to interpret for her, and on her own ability to learn from slide presentations during class. She also relies on her friends to help her complete assignments for class. Anggi reports that she has never considered asking for accommodations and is “reluctant to ask for such things.” Like her high school teachers who gave her junior high textbooks, her university lecturer gave her fewer questions on her final exam, which can be interpreted as a sign of the negative attitudes of the general population toward disabled people.

Overall, Anggi reports a “positive attitude” toward the medical system in Indonesia. She states that she has never encountered blatant discrimination or insults from health professionals. However, although she is 21 years old, she has never been to the doctor on her own. Her mother has always accompanied her to doctor’s appointments to interpret for her. Anggi says that she is “not brave enough” to go to the doctor by herself because she is afraid that miscommunication will occur and result in her receiving the “wrong medicine.” As a young healthy woman, Anggi has few health concerns.

Maria (55 Y.O)

Maria was born and raised in a remote area in East Nusa Tenggara. She became disabled in 1974 when a strong wind caused the bookshelves in her school to fall over and crush her leg. She was taken to the hospital, where they amputated her leg. She remained in the hospital for 3 months. “Feeling embarrassed” about her disability, the young Maria did not return to school for another 3 months.

Maria remembers resuming her daily activities “without so many changes.” She used a “Canadian crutch” to move around. She stated that the “biggest barrier” in her life was the attitude of her friends, who mocked and insulted her for having only one leg. She recalls that the road that she had to travel to get to school was “harsh”—hilly and full of rocks—but she was able to manage using her crutches.

When she was in seventh grade, Maria’s family moved to Atambua, the capital city of a regency in East Nusa Tenggara Province, where she attended Catholic school. There were only four disabled students in the entire school. She remembers that she “didn’t receive any discrimination and insult from other students.” However, the school’s headmaster “warn the students in the beginning of the school that whoever insult these four disabled students will be expelled.”

Maria moved to Makassar, South Sulawesi, where she met her husband, who also has a disability. She was married in 1984. When Maria became pregnant, health professionals asked: “Why do you want to have kids?” And “other people were looking [at] her like she is really weird.”

Maria attended university in 1994 for one and a half years but quit when she became pregnant with her second child. She adds that the university building was “quite inaccessible.” Her classes were held on the ninth floor and sometimes the elevator was not working. “But,” Maria states, “the professors were nice.”

At the time of the interview, Maria was the head of the Indonesian Association of Women with Disabilities, South Sulawesi. Her husband was the head of the Indonesian Association of Disabled People, South Sulawesi.

Maria prefers receiving healthcare in a private clinic, where she feels she receives the best possible treatment.

Narti (Between 40 and 50 Y.O)

Narti's age is unclear. She claims to be 40 years old, but "clearly remembered that she finished her high school in 1985." She was raised in a rural part of South Sulawesi Province, which is now an independent province, in a place called Mandar.

After finishing high school, Narti moved to Makassar to pursue her degree in Education. She became sick and quit after one semester, returning to her home. In 1991, skin sores started to appear on Narti's back. Raised in a poor, rural environment, with no mother—she died during childbirth—Narti's father and other kin—she has 12 siblings from different mothers—initially attempted to heal the sores using "traditional methods." After 2 years, the skin condition progressed to a point that it impaired her mobility. This was when "she knew that she was having leprosy and started to take medicine." She "was better, she could walk again, and her skin sores started to heal although it did leave scars in her extremities." She continued taking medication for another 2 years.

Narti was declared "clean" of the bacterium in 1995 or 1996, but the effects of leprosy continued to affect her life. In 2003, she was hospitalized for a year for a "leg problem." She remembers that most of the time the "healthcare providers were very nice and understanding." However, she could tell that some of them "was feeling disgusted by her skin sores." Narti recalls that although "they did not tell her right in the face, she could tell from the way they hold her extremities, their expression, and the way they cleaned her skin sores." She said that the most disgusted healthcare providers were usually the "newbies" or interns.

At the time of the interview, Narti was married to a man who also had leprosy, her second husband. Although she refused to talk about her first marriage, it was evident that Narti's first husband left her because of her disability.

Narti stated—with tears in her eyes—that "many people were disgusted by her condition, including her own family members." She met her husband in the hospital in 2003 and they got married in 2004. They moved to Makassar in 2006, where they live in a "leprosy community."

Narti describes herself as a "homemaker." Her husband earns his income through begging, which is a common way of living for people with leprosy and other "disfigurements."

Eka (26 Y.O)
Born in 1991, Eka began wearing glasses when she was a young girl. During her second year of high school, she started to feel pain behind her right eye. Physicians diagnosed her with glaucoma. She began taking medications, but the condition continued to progress. Eka completely lost her sight in 2011, when she was 20 years old.

Initially she was sad, but when she met other blind people and “started learning how to operate computer” she started to “feel better.” She decided to quit the university she had been attending, even though she states that because her vision loss was gradual, she was able to become accustomed to it and there was “no adaptation whatsoever.”

Through her new friendships in the blind community, Eka was able to obtain a recommendation from a prominent blind organization, Kartunet, which enabled her to attend university in Semarang, the capital city Central Java, where she resumed her studies in English literature. Having access to computer technologies, and knowing how to use them, greatly enhanced her educational experience at university.

Originally from the Brebes Regency of Central Java, Eka had to move to attend school, which meant she would no longer be living with her parents. She was able to live on her own in a kos-kosan, which is much like the dorm rooms in which university students in the USA live.

Eka states that she is able to access healthcare services and that the services are “good.” However, she relates “bad experiences” with nurses and doctors who were “rude” to her and inconsiderate of her inability to see. Eka recalls that one time when she visited a “famous eye clinic” in Bandung for a regular checkup, the nurse seemed as though she “refused to believe” that Eka was completely blind, and she proceeded with tests that Eka could not perform. When Eka complained to the physician about the nurse’s behavior, he seemed indifferent and suggested she file a complaint with the clinic.

Sometimes healthcare professionals’ dismissive and negligent behavior had serious health consequences for Eka. She states that sometimes when she saw healthcare professionals for “simple conditions (like flu, for example), the doctors… did not give her the ‘right’ medication. She always warned the doctors that she had glaucoma and please do not give her medications that would be contradictive with her condition, but every time she took the prescribed medication, she suffered adverse effect (her eye pressure increases, which leads to headache and stomachache).”

Before 2014, Eka did not have any kind of health insurance and all her health treatments had been paid for by her parents. Eka currently lives in Bangka Belitung, South Sumatra, where she is a freelance translator and “website writer.”

Conclusion

In this brief study we have noted that a significant minority of the world's population is disabled and that most disabled people live in developing countries. We have outlined the current situation in Indonesia with respect to disability and disabled people. We have shown that significant progress has been made in certain areas. Indonesia has ratified the UN CRPD and passed legislation meant to ensure the rights of people with disabilities. A number of important disabled people's organizations, non-profit organizations, and non-governmental organizations have been created in Indonesia. Significant work remains, however, in the area of changing the predominantly negative culture of disability in Indonesia. We have shown these negative attitudes in the oral interviews provided by disabled women living in Indonesia, especially as they relate to healthcare and to a lesser extent education.

While professionals such as occupational therapists and social workers have worked to empower individual disabled people and change the culture of their own work environments, and designers and architects have worked to build a more accessible built environment, we contend that global disability studies provides new avenues of intervention and new theories that will further empower disabled people, especially women and girls, in places like Indonesia. We argue that a powerful way to create more positive attitudes is through the consideration of a diverse range of life stories that include the lived experiences of disabled people. Thus, we have concluded our essay with four brief vignettes that highlight the obstacles faced by disabled women living in Indonesia, specifically in the areas of healthcare and education, and to a lesser extent housing and employment.

Questions moving forward might include: How do we build more effective communication networks among various disability communities in Indonesia? How do we bridge the significant gaps between rural and urban settings, and between middle- or upper-class Indonesians and their poor counterparts? How do we mitigate the difficulties posed by ethnic and linguistic diversity, as well as differing levels of religious conviction? What might a comparative study of disabled women and disabled men look like in Indonesia? What role can researchers play in advocating for the equal treatment of disabled people in Indonesia? And finally, how can new information that includes the thoughts and experiences of disabled people be conveyed to healthcare professionals and educators in a way that they will find useful in their daily practice?

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