

# **“BETTER DIE AT HOME THAN HERE IN THIS HOSPITAL”: EXPLORING CHALLENGES OF WOMEN WITH DISABILITIES IN ACCESSING HEALTHCARE IN MALAYSIA**

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## **Abstract**

This paper explores challenges faced by three Malaysian women with disabilities in accessing health care services. Framing the discussion from a human rights perspective, the authors start by analysing local, regional and international human rights instruments to identify existing legal framework for addressing the rights of disable women in accessing health care services. The policy analysis is then followed with an unstructured discussion with three disabled female respondents. From the conversation, four main themes emerged. These themes are, firstly, environmental and structural barriers, secondly, process barriers, thirdly, attitudinal barriers and lastly, gender insensitivity. This paper concludes by highlighting recommendations made by the respondents to improve access for disabled women with regards to accessing local health care services. Here we explore issues and challenges faced by them with an aim of making health services inclusive for Malaysian women with disabilities.

**Keywords:** women with disabilities, healthcare, environmental and structural barriers, process barriers, attitudinal barriers, gender insensitivity and access.

## **Introduction**

At the global level, women's health issues have been emphasized with the primary focus on issues such as family planning, pregnancy, cancer and non-communicable diseases (Nour 2014). The need for gender-specific research initiatives are widely acknowledged in today's world since there were significant differences in terms of causes, symptoms and treatment approaches between men and women (Grass, Weinstein and Feigenbaum 2000). Unfortunately, health care issues among women with disabilities are amongst the least to get attention in the research community. Globally speaking, there is only a handful of research that has been done regarding the situation of women with disabilities in the health care sector. In Malaysia, this topic is still vastly ignored. Thus, this article aims to explore the challenges faced by women with disabilities in using local health care services.

We outline two main objectives for this paper. First, we want to explore the existing human rights mechanisms related to women with disabilities' access to health care. Second, we want to capture the experience of three disabled women in accessing local health care services. This paper begins with the explanation on research methodology. Then,

we discuss barriers to access based on previous literature. After that, we present our analysis on the human rights instruments. Finally, we put forth the experience and suggestions for improvement from our respondents with regards to local health care services.

## Methodology

We designed the current study to be an exploratory research, which used qualitative methods. For that purpose, researchers organized a workshop in May 2016 to engage different stakeholder groups in streamlining the disability inclusivity in Malaysia and the health care for women with disabilities was one of the themes in the workshop. Even though invitation letters were sent out to different individuals and organizations, only one woman with mobility impairment and two women with visual impairment attended the workshop. Two of them are married. The woman with mobility impairment was a high-ranking government officer. For the two women with visual impairment, one was a representative from a Disabled People's Organization (DPO) while the other was a university student. This small yet diverse group of research participants can offer fruitful information, especially in the form of their experiences, related to their access to health care in Malaysia.

For this study, the researchers employed qualitative method through group discussion. The discussion was conducted using an interview schedule to enable researchers to get richer and deeper information from our respondents. As for the secondary data analysis, researchers also examined the selected materials related to health care provision for women with disabilities at three levels -international, regional and local. For international-level materials, the researchers selected and analysed human rights instruments such as declarations, conventions and covenants produced by the United Nations (UN). As for the regional-level materials, the researchers focused more on the declarations made by the Association of Southeast Asian Nations (ASEAN). Finally, for the local-level materials, the researchers looked into the National Policy of Persons with Disabilities 2007 and Persons with Disabilities Act 2008. By reviewing these documents, researchers were able to contextualize the issue of access to health care for women with disabilities at the international, regional and local levels. This does not only help the researchers in identifying legal and human rights framework on health care provision for persons with disabilities, particularly women with disabilities, but also served as critical resources for advocacy. The researchers used thematic analysis to analyse the data gathered from the group discussion with the three women with disabilities.

In the thematic analysis, the themes were developed from the past literature on forms of barriers to healthcare which is environmental-structural barriers, process barriers and sociodemographic barriers. In the policy review, we looked for keywords related to structure of governance, health care (such as rehabilitation) and accessibility.

## Literature Review

Neglect against women is often associated with imbalances in the socio-economic sphere that can affect an individual's socioeconomic status (Thorbecke & Charumilin 2002). This persistent negligence eventually leads to socio-economic inequalities, especially in terms of health care. A white paper prepared by the International Council of Women's Health Issues reported that women's health is in serious condition due to the lack of reliable data as well as inequalities faced by this group in access to education, employment, transportation and so forth (Davidson, McGrath, Meleis, Stern, DiGiacomo, Dharmendra, Correa-de-Araujo, Campbell, Hochleitner, Messias, Brown, Teitelman, Sindhu, Reesman, Richter, Sommers, Schaeffer, Stringer, Sampselle, Anderson, Tuazon, Cao & Covan 2011).

From the human rights lens, rights to health care is part of any human rights conventions because of its linkages with other forms of socioeconomic rights such as rights to education and rights to employment (Heymann, Cassola, Raub, & Mishra 2013: 639-640). Women are more likely to be poor compared to men because they engage in low wage jobs (Woods, 1995: 17) and this situation makes them vulnerable to diseases (World Health Organization 2009). Women's inability to access proper health care is also caused by subjective social deprivation which is tightly linked to social norms, culture, religious belief, political view and individual characteristics (Siti Hajar Abu Bakar, Noralina Omar, Abd Hadi Zakaria & Haris Abd Wahab 2012: 33; Woods 1995: 19).

In the health care sector, women with disabilities are likely to face greater marginalization. Women with disabilities are usually perceived as weak due to their gender and disability. As a result, women with disabilities are often viewed and labelled as passive and helpless (Meekosha 2004: 4). Due to this disablement, women with disabilities, especially young girls, have always been denied their rights to access a range of services including rehabilitation services (Meekosha 2004: 4-5). In India, for example, women with disabilities had to deal with

inequalities in terms of health care and decision-making, and they are prone to threat of violence and abuse (Nandhi, Sathpathy & Hans 2007).

Scholarship on the issue of health care among women with disabilities in Malaysia is limited. The only study was conducted by Aizan Sofia Amin and Jamiah Manap (2015) entitled "*Geografi, Kemiskinan dan Wanita Kurang Upaya*" di Malaysia and a proceeding paper presented by Azlinda Baroni, Anisah Che Ngah & Noraihan Mohd Nordin (2018) entitled "Women patients with disabilities in maternal health care: The rights of decision making in continuing and termination of pregnancy in Malaysia" in the recent 4<sup>th</sup> Putrajaya International Conference on Children, Women, Elderly and People with Disabilities.

In the first study by Aizan Sofia Amin and Jamiah Manap (2015), they found that geographical factors, poverty and disability affected the disabled women's lives especially in terms of their health, education and employment. They also found that most women with disabilities are born into poor families and living in rural areas. Lack of financial resources and accessible transportation restricted their access to health care services where most of the services are located in urban areas. Consequently, those who have symptoms of illness or injury could not seek medical treatment at an early stage and eventually become permanently impaired.

Women with disabilities were often plagued with different obstacles in accessing health care services. The challenges to access healthcare services can be divided into three forms of barriers: environmental-structural, process and socio-demographic. Environmental-structural barriers refer to the structural obstacles that are directly related to the number, type, concentration, location, or the structure of service providers' organizations (Rooy, Amadhila, Mufun, Swartz, Mannan & MacLachlan 2012). This includes issues such as geographical accessibility, financial factors, as well as the location and technology (Esser-Stuart & Lyons 2012). In short, it is closely related to environmental and architectural barriers that affect the ability of a woman with disability to move around and to access their surroundings.

Environmental-structural barriers also exist due to unsuitable and inaccessible equipment for cancer detection (World Health Organization & World Bank 2011) and inaccessible health promotion programs for women with disabilities (Odette, Israel, Lee, Ullman, Colontonio, Maclean & Locker 2003). Besides that, vast geographical coverage also posts another challenge in health care provision for disabled persons. For that, Nualneltr and Sakhornkhan (2012) suggest that rural volunteers should be empowered in meeting this need in rural areas.

Meanwhile, process barriers refer to obstacles associated with the process of service delivery (Scheer, Kroll, Neri & Beatty 2003). These include language, lack of knowledge among service providers and the long waiting time (Odette et al. 2003). For example, the limited number of sign language interpreters restricted those who are deaf to interact with doctors. This situation could lead to misunderstanding and the disabled patient was likely to get the wrong treatment (Haricharan, Coomans & London 2013: 62). Communication barriers between disabled patients with doctors and nurses will also gravely affect the access to health care services, especially among persons with learning disabilities (Lin, Lin Chu & Chen 2011: 149-150).

The third obstacle is socio-demographic barriers. In contrast to the two forms of barriers described above, socio-demographic barriers focus on factors such as the individual's cultural background, level of education and profession. The level of education is considered the main factor that made women with disabilities unable to access information with regards to their disease, available health care services or medicine (Ramjan, Cotton, Algosio & Peters 2015).

## **Policy on Disabilities' and Rights to Healthcare**

In this section, we discuss the human rights instruments and policies. These documents are important in identifying the basis of human rights and framework for legally-binding measures in terms of persons with disabilities' rights to health-related services in Malaysia. For international-level documents, researchers used and analysed human rights instruments produced by the United Nations. As for the regional-level documents, ASEAN's documents are used for secondary data analysis. Finally, for local-level documents, we used and reviewed National Policy of Persons with Disabilities 2007 and Persons with Disabilities Act 2008.

We divided this section into two subsections. First, we looked at the mechanisms developed at international and regional levels, which can be used as a framework by persons with disabilities in advocating and influencing their governments on the provision of accessible and equitable health care for this minority group. The second subsection looked at the application and translation of the international and regional commitment by the Malaysian government with regards to the rights of Malaysians with disabilities to an inclusive healthcare system.

### *International and regional mechanisms*

At the international level, the right of each individual is inherent and inalienable as recognized by the Universal Declaration of Human Rights 1948 (UDHR). In Article 1 and Article 2, the UDHR recognizes that each individual has the freedom and shares equal rights regardless of their backgrounds, and this includes people with disabilities. The right to health care is enshrined in Article 25 of the UDHR. Consequently, women either with or without disabilities are entitled to care and assistance to attain healthy life. In addition, Sub Article 1 of Article 12 in the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR) recognizes the right of each person to enjoy physical and mental health at the highest level.

Despite various international documents that have been introduced and signed, the gap of gender inequalities is still significant between men and women. This also applies to health inequality between these two groups (see for example Woods 1995). One of the reasons for this is that the term on right to health is written in a general statement but the rights of women are not explicitly mentioned. The Convention on the Elimination of All Forms of Discrimination against Women 1981 (CEDAW) was then produced to ensure equality and rights of women. CEDAW is an instrument of advocacy, strategy and policy development tools specifically for women that are ratified by many countries throughout the world. Among other things, Article 12 of the CEDAW also touches on the rights and interests of women to health care services. The Article clearly states the need for health care provision during pregnancy, after childbirth and family planning.

When touching on the rights of people with disabilities, the most important document is nonetheless the Convention on the Rights of Persons with Disabilities 2006 (CRPD), which recognized the state parties' obligations to protect the rights of persons with disabilities in various aspects. CRPD puts the value of equality between men and women as part of its principles. In the health care context, Article 25 of the CRPD stresses the role of government to take appropriate measures in ensuring full and effective access of people with disabilities to health services without neglecting the need for gender-sensitivity.

These various UN human rights documents are adopted and supported by majority of the world's nations which has become an important reference, if not explicitly, for the different regional association of different continents. The Association of South East Asian Nations (ASEAN) also made the same pledge on human rights issues. Through the adoption of the ASEAN Human Rights Declaration in 2012, Southeast Asia as region now has its own regional human rights framework. In the general principles of 1, 2 and 4, the Declaration recognizes that each individual are born with freedom with shared equal rights and dignity irrespective of their social backgrounds and this includes minority groups such as people with disabilities. This Declaration also divided human rights into several categories and one of it is economic, social and cultural rights in which it recognizes the right to health care through sub-article D under Article 28 and sub-article 1 under Article 29.

Issues on women have been an area of concern in the Southeast Asia since late 1980s. This can be seen from the 1988 Declaration of the Advancement of Women in the ASEAN Region. Articles 1, 2 and 3 of this Declaration recognize the importance of active participation and integration of women in this region in sharing the future development and progress, as well as to meet the needs and aspirations of women among the ASEAN Member States. Apart from the 1988 Declaration, Article 8 in the Hanoi Declaration on the Enhancement of Welfare and Development of ASEAN Women and Children (ASEAN Secretariat, 2010) also addressed women's health care which includes access to reproductive health and other services.

The latest development in the region is the Bali Declaration on the Enhancement of the Role and Participation of Persons with Disabilities in ASEAN Communities in 2011 (ASEAN Secretariat 2011). Article 5 of the Bali Declaration stipulates that ASEAN Member States are to ensure the fulfilment of persons with disabilities' rights in every aspect of their lives. Moreover, in the Mobilization Framework of the ASEAN Decade of Persons with Disabilities 2011-2020, issues related to health care, rehabilitation, which also includes community-based rehabilitation (CBR) and women's issues are addressed under the ASEAN Socio-Cultural Community (ASCC), particularly through priority areas of 5 and 10.

### *Practice in Malaysia*

Malaysian government is a signatory state to CEDAW and CRPD. CEDAW was signed in 1995 with several reservations. Subsequently in 2008, the Malaysian government signed the CRPD and ratified it two years later. Prior to that, the Malaysian government through the Ministry of Women, Family and Community Development developed the Policy of Persons with Disabilities 2007 and the parliament passed the Persons with Disabilities Act 2008. The

introduction and adoption of CRPD by UN pushed many governments in the world, including Malaysia to take at least some systemic actions. In the Malaysia context, policy, legislation and plan of action for persons with disabilities were introduced.

In the Persons with Disabilities Act 2008, subsection 1 of Section 35 states that every person with disabilities has a right to access health care services on equal basis with other citizens (Malaysia 2008). This emphasis is aligned with the policy statement mentioned in the 2007 National Policy for Persons with Disabilities, which served as a basis for equal human rights and opportunity among Malaysians with disabilities to fully participate in their society (Ministry of Women, Family & Community Development 2007). Furthermore, subsection 2 of Section 35 in the Persons with Disabilities Act 2008 also highlights the need for gender-sensitive health care services for persons with disabilities (Malaysia 2008). Both the National Policy of Persons with Disabilities 2007 and the Persons with Disabilities Act 2008 shared similarities on the foundation of health care provision for women with disabilities. This consistency shows that the Malaysian government has a clear view at the philosophical level, regarding health care provision for persons with disabilities in this country. The National Policy was written during the development of the Persons with Disabilities Act 2008 and this National Policy served as foundation for government strategic planning in regards to disabled people's inclusivity in Malaysia. This was clear in Plan of Action for Persons with Disabilities 2008-2012 through its third core strategy.

In 2016, the Malaysian government launched the Plan of Action for Persons with Disabilities 2016-2022, which was based on the 2007's policy and Incheon Strategy. Incheon Strategy is the third ten-year action plan developed by UNESCAP on the inclusion of persons with disabilities in Asia-Pacific region. Healthcare is placed as the fifth goal under the Incheon Strategy. Under the Plan of Action for Persons with Disabilities 2016-2022, healthcare issues are placed as the fourth core strategy.

There is no clear indication with regards to health facilities and service accessibility in Section 35 of the Persons with Disabilities Act 2008. In terms of healthcare services, clauses under Section 26 of the Act state that: "(1) Persons with disabilities shall have the right to access and use of, public facilities, amenities, services and buildings open or provided to the public on equal basis with persons without disabilities, but subject to the existence or emergence of such situations that may endanger the safety of persons with disabilities. (2) For the purposes of subsection (1), the Government and the providers of such public facilities, amenities, services and buildings shall give appropriate consideration and take necessary measures to ensure that such public facilities, amenities, services and buildings and the improvement of the equipment related there to conform to universal design in order to facilitate their access and use by persons with disabilities" (Malaysia 2008).

The specific focus on access to buildings, services and amenities could be interpreted in ways that are concerning health care services, in which the right to access public buildings including clinics and hospitals are important. On the connectivity issues, Section 27 states that: "(1) Persons with disabilities shall have the right to access and use public transport facilities, amenities and services open or provided to the public on equal basis with persons without disabilities (2) For the purposes of subsection (1), the Government and the providers of such public transport facilities, amenities and services shall give appropriate consideration and take necessary measures to ensure that such facilities, amenities and services conform to universal design in order to facilitate their access and use by persons with disabilities" (Malaysia 2008), which in turn can be used since this section was applicable to all forms of transport facilities such as buses, taxis and trains. Thus, persons with disabilities can perform their right to commute freely in their own country as enshrined in the Federal Constitution of Malaysia.

Even though the responsibilities of all relevant ministries and government agencies have been listed down clearly in Section 15 and that, the National Council for Persons with Disabilities has power in regards to disabled Malaysians' affairs as stipulated in Section 9; there are still several major flaws to this Act for it to be effectively implemented.

First, there is no clear provision in regards to government's obligation to practice inclusive budgeting by including the costs of providing support services and related necessities (for example staffs training, expertise development and awareness programs) on healthcare for Malaysians with disabilities in national budgets, or even in any sector mentioned in the act such as infrastructure, education, employment, sports etc. In other words, there is no specific clause in the Persons with Disabilities Act 2008 that requires all ministries and relevant government agencies to include Malaysians with disabilities' affairs in their annual budget. Without this clause, it poses a huge challenge to achieve inclusivity for persons with disabilities in the country since no funding is allocated to organize and provide needed services by persons with disabilities.

Second, the minister in charge of persons with disabilities' affairs has no 'final say' in any issues that may arise. This act was amongst the act that tried to promote multi-sectoral collaboration which can be seen in Article 15 that states: "It shall be the responsibility and obligation of every relevant ministries, government agencies or bodies or

organizations (a) to co-operate with and assist the Council in the performance by the Council of its functions under this Act; (b) to give due consideration to the national policy and national plan of action of the Government relating to persons with disabilities; and (c) to undertake steps, measures or actions required to be taken by it in such form or manner as may be provided for under any other written law or otherwise relating to persons with disabilities” (Malaysia 2008). On surface, the mentioned article looks good. Nevertheless, the minister in charge of persons with disabilities’ affairs would not be able to overrule or to make final decision in any case if all do not agree to the collaboration. This situation poses a huge challenge to the development process towards inclusivity for persons with disabilities.

## **Voices from the Ground**

From the unstructured discussion with our respondents, two challenges that prevented women with disabilities from accessing health care were identified. These two challenges, which are also called barriers, are environmental-structural and process barriers. In addition, there are two other barriers that are frequently faced by these women; they are gender insensitivity and attitudinal barriers. Apart from that, recommendations made by the research participants are also listed in order to improve local healthcare sector so that it can be accessible to women with disabilities.

As mentioned above, there are three research participants in this research. First is Suzita. Suzita is a wheelchair user and currently working as civil servant with a high-ranking position. She is married and has children. She graduated from a local public university. The second participant is Rita. Rita is partially sighted. She is married and has no children yet. Rita, during that time, worked at a national-level DPO for persons with visual impairment for more than five years. Third participant is Alisha. She is a university student with visual impairment. During the discussion, she was in her undergraduate studies. She is single. These three participants are regulars in getting medical check-up treatments.

### ***Environmental-Structural Barrier***

The results of the group discussion found that Suzita and Rita face difficulty in getting treatment for various reasons, for example the difficulty in accessing the room and equipment, as well as the absence of transportation. This situation depends on the type of defect and design of the hospital. For example, women with physical disabilities are less likely to access the building as mentioned by Suzita:

“Facilities, there is no direction... [difficult to find] for blood clinic, x-ray room... there is no direction. I cannot transfer myself up to the bed since the bed is too high for me. Want to have x-ray examination is also difficult” (Suzita/ Physical/ Married)

Rita also added this point by saying:

“Transport [is one of the constraints]. So, when I reach there, I have to find the information desk. For the first time, I have to bring an assistant with me. He or she will then explain the surrounding, how to get from one place to another because the next time the assistant might not be able to help.” (Rita/ Blind/ Married)

Inaccessible transportation, hospital and clinic buildings and unsuitable equipment or facilities are among the major components in environmental-structural barrier. These components are the preliminary indicators whether persons with disabilities able to access the services.

### ***Process Barrier***

In addition to environmental-structural barriers, knowledge among health care providers is also another factor that discourages women with disabilities to seek treatment. The findings indicate that most health care providers such as

doctors still lack awareness in understanding the needs of disabled women. Rita shared how good assistance can make it better for her to access health care services:

"Service, some places are good, others not so much... One example, there is one nurse at this one clinic, probably because she knew me; she would tell the number [to know my turn]. The nurse will come out to take me to the room." (Rita/ Blind/ Married)

However, for Alisha, she had a different experience. She shared:

"During a blood test once, there is a doctor who kept on taking my blood [without any consultation]. I felt so shock. But I was so tired so I could not afford to fight." (Alisha/ Blind/ Single)

From the responses presented above, both Rita and Alisha had a different experience. Low level of sensitivity among the health care providers and professionals contributes to process barriers. The situation may be worse if the health care providers and professionals have a negative attitude, perception and belief toward persons with disabilities. It will then reflect in their treatments to this vulnerable group. It also to a certain extent indicates that persons with disabilities have to rely on the goodwill and common sense of whoever is treating them. This then highlights the importance of sensitization program and standard service procedure for persons with disabilities that should be developed.

### ***Gender Insensitivity***

The results of the group discussion also found that the dilemma that often plague women with disabilities to get healthcare is also caused by the lack of gender sensitivity among service providers on the needs of disabled women. In addition to the denial of their rights and dignity, some of them feel uncomfortable. This is reflected from the following statement:

"[before this] at one hospital, during night time ... you have to call a doctor. But they did not ask permission [when he wants to come in]. Suddenly he just entered my room. I do not have time to wear hijab. The doctor is a man. Another time, I went for a check-up, he wants to check here and there on my body without asking my permission first. Actually, I did request a female doctor." (Suzita/ Physical/ Married)

Low level of sensitivity among health care providers and professionals can also lead to gender insensitivity problem. Service-related industries, such as health care should practice ethics when delivering their services to a wide range of consumers. This includes gender sensitivity. Hence, this calls for continuous and aggressive sensitization programme that incorporates aspects such as gender sensitivity.

### ***Attitudinal Barrier***

The last obstacle to women with disabilities to access healthcare is the negative attitude shown by the service providers. Some of the research participants explained ignorance displayed by some nurses without any regard of their feelings.

"One time, I was admitted into hospital, I told a nurse there that I'm low vision. She just said its okay, you can see a little bit so you go around on your own. She thought we could move ourselves just like that. Even partially blind need some guidance [orientation] to go around for the first time." (Rita/ Blind/ Married)

As stated earlier, negative attitude towards a group of individuals can lead to the issue of poor treatment. This may be caused by ignorance or negative socialization (e.g. listening to bad things from other people). For that, awareness programmes should be organised continuously in addition to the sensitization programmes.

In linking back this section to the policy review presented in the previous section, two issues are brought to our attention: diversity and intersection. From the group discussion, it is clear that different categories of impairment need different forms of support and this proved the existence of diversity even in the disabled community. This fact was also enshrined in the UN declarations and ASEAN declarations. However, this does not mean that those declarations reflect the “fact of diversity” in this non-homogenous group of persons with disabilities. This then brings to the urgency to carefully and systematically address these diverse needs. For women with disabilities, this issue is further complicated by the gender and impairment factors.

Even though the UN and ASEAN declarations have explicitly mentioned the existence of multiple dimensions of human life (e.g. social, economy, politic and environment) but unfortunately, the linkages between those dimensions and its importance are not explicitly expressed in those documents. Hence, this disrupted the promotion for inclusive and holistic intervention in a particular issue of a particular social group. From the group discussion above, the intersection between transportation system to the hospital or clinic, then to the accessibility issues of the internal interior of the medical facilities are inter-related and impacts on access. Intersection does not only refer to environmental, economic and political aspects, but also include the socio-cultural aspect. As argued in the previous section, there was no explicit clause in the Persons with Disabilities Act 2008, which addresses the duty of the government agencies to practice inclusive budgeting. Even such awareness of its magnitude and importance is absent. The law is also unclear about the duty of government on capacity and expertise development on disability issues.

### **Suggested Recommendations**

At the end of the group discussion, there are a number of proposals that was put forward by the research participants to improve health care services in the country. The first proposal is concerned with the policy. Policies must be established taking into account the interests of disabled women. Any policies in place should be made aware and adopted by all clinics and hospitals in the country, be it in the public or private sectors.

They also recommended establishing the post of assistant at each clinic and hospital to help women with disabilities when they come to health care centres. This is to ensure that they can access the service comfortably without any constraints. Sensitization trainings were also mentioned frequently in the discussion. Hence, awareness training for nurses and doctors should be organized so that these individuals can be more sensitive and aware of the needs of disabled patients. Such sensitization includes knowledge on how to assist different categories of persons with disabilities, accessibility issues and emergency.

Another suggestion is regarding the accessibility to information on matters such as directions and announcements. This is to avoid any confusion among consumers, especially women with disabilities. This situation can also prevent them from relying too much on others that may cause them to see themselves as a burden to other people in their surroundings.

### **Conclusion**

It is evident that everyone’s rights to gain highest attainable level of healthcare are recognized through abundance of human rights instruments, both at international level and at the regional level. However, despite the policies and the Persons with Disabilities Act 2008 that are currently in place, Malaysia is still facing huge lag in streamlining inclusivity in its health care sector. As a result, persons with disabilities, especially women, are unable to fully enjoy their rights as citizens of this country to use health services as offered to others. Four main issues as identified should be given serious attention and urgent action should be taken. These issues are environmental-structural barrier, process barrier, attitudinal barrier and gender insensitivity. Proactive measures such as policy development, continuous sensitization training programs for medical staff and doctors, information provision and infrastructural improvements are some of the steps that could be taken to ensure full enjoyment of persons with disabilities to health care services.

The government and healthcare providers should also view healthcare provision from the perspective of human rights and not perceive it as merely “a product for sale”. On the other hand, health care issues for women with disabilities must also be viewed from an intersectional perspective where it is located at the intersection of the social,



cultural, biological, political and economic aspect of human life. By acknowledging these intersections, it can facilitate the framework in solving obstacles faced by women with disabilities in accessing health care services in Malaysia. For that, a holistic approach of intervention, user consultation and multi-stakeholder collaboration should be practiced among all parties involved in this matter.

As a starter, government must re-assess and develop a clear and equitable policy on health care for persons with disabilities. Continuous sensitization training must also be conducted for doctors, nurses, medical assistants and other related officials. Besides that, sufficient funding must also be allocated to improve facilities and renovate buildings according to universal design standards. The same policy, training and accessibility assurance should also be enforced on private health care providers through regulations.

To solve the issues of diversity and intersectionality introduced above, we suggest applying the biopsychosocial model of disability and twin-track approach. To put it simply, biopsychosocial model of disability gives equal attention to the element of one's impairment, the experience from living with impairment as well as social and environmental barriers. On the other hand, twin-track approach concerns with the empowerment of the disabled community and the enablement of the society and the environment to create an inclusive society. Empowerment includes capacity building and the ability to make decision, while enablement can be translated into policies, legislations, infrastructure and attitude.

This research serves as a stepping-stone to further exploration on issues related to health care among Malaysian women with disabilities. There are still a lot of gaps that must be filled, as this research is only able to capture some of the experiences faced by three Malaysian women with disabilities in accessing health care services based on the review of the human rights and policy instruments. One subtopic under health care that also need serious attention is rehabilitation services. This is due to the fact that rehabilitation services are a necessary part of intervention for persons with disabilities, especially those who are adventitiously impaired. With ongoing research, not only we can identify more obstacles and its solutions, but also take us a step closer in ensuring inclusivity in access to health care for all citizens in this country.

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## Endnotes

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## References

- Aizan Sofia Amin & Jamiah Manap. 2015. Geografi, Kemiskinan dan Wanita Kurang Upaya di Malaysia. *Malaysian Journal Society & Space*, 11:7, 82-91.
- ASEAN Secretariat. 2012. ASEAN Human Rights Declaration. Jakarta.
- ASEAN Secretariat. 2011. Bali Declaration on the Enhancement of the Role and Participation of the Persons with Disabilities in ASEAN Communities. Jakarta.
- ASEAN Secretariat. 2010. Ha Noi Declaration on the Enhancement of Welfare and Development of ASEAN Women and Children. Vietnam.
- ASEAN Secretariat. 1988. Declaration of the Advancement of Women in the ASEAN Region. Jakarta

- Azlinda Baroni, Anisah Che Ngah & Noraihan Mohd Nordin. 2018. *Women Patients with Disabilities in Maternal Health Care: The Rights of Decision Making in Continuing and Termination of Pregnancy in Malaysia*, a paper presented at the 4<sup>th</sup> Putrajaya International Conference on Children, Women, Elderly & Persons with Disabilities, 24-25 Februari, Hotel Bangi-Putrajaya.
- Davidson, P.M., McGrath, S.J., Meleis, A.I., Stern, P., DiGiacomo, M., Dharmendra, T., Correa-de-Araujo, R., Campbell, J.C., Hochleitner, M., Messias, D.K.H., Brown, H., Teitelman, A., Sindhu, S., Reesman, K., Richter, S., Sommers, M.S., Schaeffer, D., Stringer, M., Sampsel, C., Anderson, D., Tuazon, J.A., Cao, Y., & Covan, E.K. 2011. The Health of Women and Girls Determines the Health and Well-being of our Modern World: A White Paper from the International Council on Women's Health Issues, *Health Care for Women International*, 32:10, 870-886.
- Esser-Stuart J.E., & Lyons, M.A. 2002. Barriers and Influences in Seeking Health Care among Lower Income Minority Women. *Social Work in Health Care*, 35:3, 85-99.
- Grass, R., Weinstein, E., & Feigenbaum, R. 2000. A Research Revolution in Women's Health. *Journal of Prevention and Intervention in the Community*, 21:1, 9-27.
- Heymann, J., Cassola, A., Raub, A. & Mishra, L. 2013. Constitutional Rights to Health, Public Health and Medical Care: The Status of Health Protections in 191 countries, *Global Public Health*, 8:6, 639-653.
- Lin, L., Lin, J., Chu, C.M., & Chen, L. 2011. Caregiver Attitudes to Gynaecological Health of Women with Intellectual Disability, *Journal of Intellectual and Developmental Disability*, 36:3, 149-155.
- Malaysia. 2008. Persons with Disabilities Act. Putrajaya.
- Meekosha, H. 2004. Gender and Disability. [Online] Accessed from <http://disability-studies.leeds.ac.uk/files/library/meekosha-meekosha.pdf> on 15 August 2015
- Ministry of Women, Family & Community Development. 2007. Policy of Persons with Disabilities. Kuala Lumpur.
- Nandy, D., Sathpathy S., & Hans, N. 2007. A Multi State Socio Economic Study of Women with Disabilities in India. [Online] Government of India, UNDP & Shanta Memorial Rehabilitation Centre. Accessed from [http://www.undp.org/content/dam/india/docs/a\\_multi\\_state\\_socio\\_economic\\_study\\_of\\_with\\_disabilities\\_in\\_india.pdf](http://www.undp.org/content/dam/india/docs/a_multi_state_socio_economic_study_of_with_disabilities_in_india.pdf) on 16 August 2015.
- Nualnetr, N. and Sakhornkhan, A., 2012. Improving Accessibility to Medical Services for Persons with Disabilities in Thailand. *Disability, CBR & Inclusive Development*, 23(1), 4-49.
- Nour, N.M. 2014. Global Women's Health - A Global Perspective. *Scandinavian Journal of Clinical and Laboratory Investigation*. 74:sup244, 8-12.
- Odette, F., Israel, P., Li, A., Ullman, D., Colantonio, A., Maclean, H., & Locker, D. 2003. Barriers to Wellness Activities for Canadian Women with Physical Disabilities. *Health Care for Women International*, 24:2, 125-134.
- Ramjan, L., Cotton, A., Algosio, M., & Peters, K. 2015. Barriers to Breast and Cervical Cancer Screening for Women with Physical Disability: A Review. *Women & Health*, 1-27.
- Rooy, G.V., Amadhila, E.M., Mufune, P., Swartz, L., Mannan, H., & MacLachlan, M. 2012. Perceived Barriers to Accessing Health Services among People with Disabilities in Rural Northern Namibia. *Disability & Society*, 27:6, 761-775.
- Scheer, J., Kröll, T., Neri, M.T., & Beatty, P. 2003. Access Barriers for Persons with Disabilities. *Journal for Disability Policy Studies*, 13(4), 221 -230.
- Siti Hajar Abu Bakar, Noralina Omar, Abd. Hadi Zakaria & Haris Abd Wahab. 2012. Intervensi Sosial untuk Komuniti Tersisih: Ke Arah Pembangunan Ummah, *Jurnal Hadhari*, 4:2, 29-44.
- Thorbecke, E., & Charumilind, C. 2002. Economic Inequality and Its Socioeconomic Impact. *World Development*, 30:9, 1477-1495.
- United Nations. 2006. Convention on the Rights of Persons with Disabilities. Geneva.
- United Nations. 1981. Convention on the Elimination of All Forms of Discrimination against Women. Geneva.
- United Nations. 1966. International Covenant on Economic, Social and Cultural Rights. Geneva.
- United Nations. 1948. Universal Declaration on Human Rights. Geneva.
- Woods, N.F. 1995. Women and Their Health, in *Women's Health Care: A Comprehensive Handbook*, Fogel, C.I. & Woods, N.F. (eds), London & New Delhi: Sage Publications, 1-22.
- World Health Organization. 2009. *Women Health: Today's Evidence Tomorrow's Agenda*. Geneva: World Health Organization.
- World Health Organization and World Bank. 2011. *The World Health Report on Disability*. Geneva: World Health Organization.