

Title : First Dive into the Visually Impaired Community

Author(s) : Sarah Aida binti Jasmedon

Institution : University of Malaya

Category : Article, Competition

Topics : Anthropology

Sarah Aida Binti Jasmedon

University of Malaya

sarahaidaj@gmail.com

First Dive into the Visually Impaired Community

I Didn't Know What to Expect

I have no idea where to start for this project. For someone who is very new in this field and has never done any academic research, I must admit; it is very daunting. Of course, I had the general idea of what I wanted to know. However, for me to arrange the thoughts and putting that on paper is another matter that I struggle with. As time passes by, I've picked up tiny pieces throughout the semester that can help me look into the community in more depth than what was said during the interviews. For starters, I wanted to know the differences between the community than the ones I'm used to seeing. The only People with Disability (PWD) community I was exposed to was the autistic and Down syndrome community, even then, I wasn't too involved with them ever since my mother had passed in 2008. My mother was the one who was always involved and encouraged my autistic brother to be sociable. I decided to follow in her footsteps in that sense. In the initial proposal, I listed out the following questions that may open the door to this community: (1) how the certified OKU people of Malaysia lives their life? (2) What are governmental supports had they received? Is it accessible? How much does it cost? Is it difficult to get accepted? What are the procedures? (3) What are the things that they wish to be more known by the public? (4) How the public reacts to your OKU state? (5) Do public

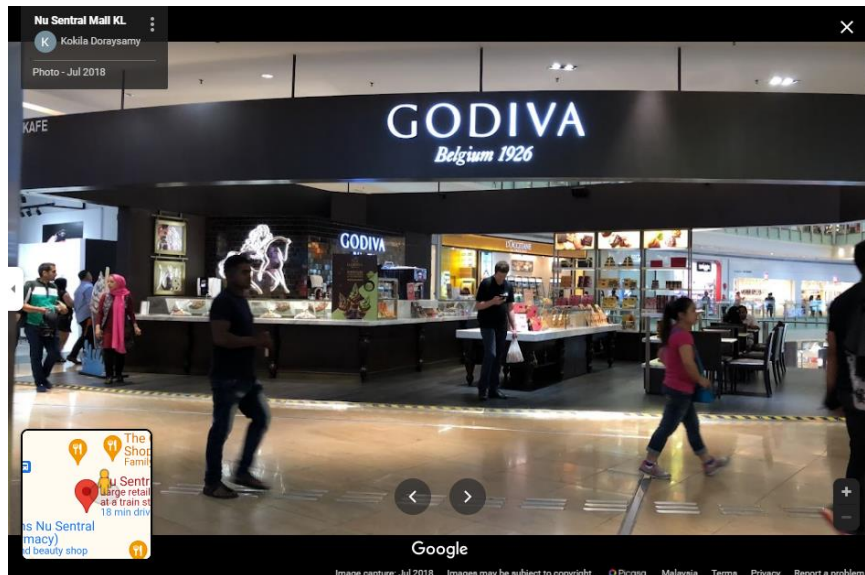
transport/facilities meet the OKU's comfort standard? (6) What are the things they hope Malaysia to improve for OKU people? (7) Why reaching out to NGOs instead of the government? By having these questions in mind, I had maneuvered my way and imagine it the best I can in these circumstances. I wasn't able to immerse myself in their daily life as planned due to the restrictions in place during the Malaysian Movement Control Order (MCO) in early 2021.

The initial plan was for me to observe them at Malaysia Association for the Blind (MAB) in Brickfields. MAB is an institute where they provide services to the visually impaired from kindergarten to old age. Established in 1951 by the Malaysia Department of Social Welfare, MAB has been the primary chosen institution by many visually impaired in Malaysia for their educational programs, vocational training, rehabilitation courses, and employment placements. The accessibility of the city also very much favors them. Other than in Kuala Lumpur, they also situated in Temerloh, Pahang and Batu Gajah, Perak. It is only logical for me to choose this place as a starting point for me to start my research project. However, due to the pandemic situation getting worst, I've decided to change my approach of collecting data by interview rather than observation. Ideally, it would be great if I can watch their interactions going through their lessons in MAB with the addition to interview them when needed. With the unpredictable circumstances, I would make do with all the resources taken from the interviews.

A Glimpse into a New World

On 30th March 2021, I made my way towards MAB institutes for my first day of doing academic fieldwork. The task itself was very new for I was very worried I might accidentally make offensive remarks since I was about to communicate with an unfamiliar community. On my way there, I've noted it was very easy from my home. When I've arrived at KL Sentral, I walked into NU Sentral which is also a mall that connected KL Sentral and the monorail. Arriving at the monorail station, I only need to go to the first stop of the line, which was the Tun Sambathan stop. I would like to note that; when I stepped into KL Sentral, there are tactile from

the cable cars to the platform and the inside of the terminal, even in NU Sentral Mall. However, in the mall, the tactile tiles weren't everywhere in the mall. It is only visible from KL Sentral into NU Sentral that leads to the monorail station. Other than that, there is no more tactile elsewhere in the mall.



In front of a store in NU Sentral, where the tactile tiles can be seen at the bottom of the picture. On the left of the picture is the entrance to KL Sentral. To go to the monorail station, one must follow the tactile towards the right of the picture.

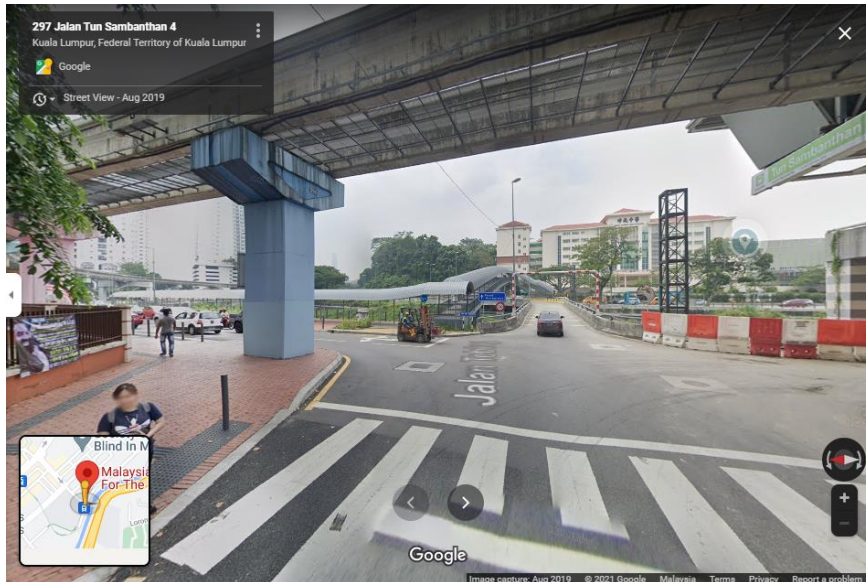
Source: Google Map.

After that, I exited the terminal and walked straight ahead, crossed a small road, and there you go! The building presents itself. I can see it from the monorail terminal. I've noted that on the little road I've crossed from the terminal, there was no traffic light that can help the visually impaired. This is very concerning; even though when I've arrived there, the road was relatively quiet, and it is still very dangerous to cross if a visually impaired was alone.



Notice there is no traffic light in this side of the road.

Source: Google Map



And neither on this side of the road

Source: Google Map.

There was a walking bridge, but it is situated further down the road.



The walking bridge is the one I had marked with red line.

Source: Google Map.

Along the way towards the MAB building, I've noticed something different; the tactile were not yellow! I am used to seeing them in yellow as you can also see it everywhere around Kuala Lumpur. I've seen black tactile in a building before, it's in NU Sentral, but I supposed that's because the floor tiles are black. I suspected it to be an effort to make the floor look neat. For

tactile on the sidewalk of the roads, this is my first time seeing it in black-colored. After some readings, I couldn't find the reason why it is black instead of the usual yellow color.

My appointment was scheduled at 10:30 am; however, since I've never been to the institute, I was worried I might get lost along the way there. Without delay, I managed to arrive at the establishment without a hitch. Along the walk towards the reception, I noticed at the side of it, there was a sensory garden. It looks so cozy; sadly, I didn't take a picture of it though. When I've arrived at the reception area, I noted that it is quite spacious than I thought it would be. On the opposite side of the front door lays the receptionist table, where 3 individuals were stationed; 2 Indian men and 1 Malay lady. While the lady was in the call to announce my arrival, I took a look around. All 3 of them are visually impaired. There were 2 big and heavy-looking machines in front of them; it looks to be specially made for the visually impaired. I was fully aware I was early, but something tells me I need to announce my arrival despite it. While waiting, I took some photos of products displayed there. There are mostly weaved stools¹. They are very colorful too! I'm guessing they were done by the students here. I also took home most of the brochures there, most are from Tun Hussein Onn National Eye Hospital where they educate the public about eye diseases, treatments, therapy, etc. Around 10:05 am an Indian woman had walked in backward while directing an Indian child; it turns out she was guiding a child into space. She was so small; they had been talking to the receptionist in Tamil, English and, Malay.

She was five years old named Sashista. I am guessing she's a frequent visitor here due to how friendly the receptionist and the mother were. They asked her many things and even asked her to sing for them. She did, and it was a very cute sight to witness. To sum up our discussion that day, I concluded, they offer many learning assistance including the Braille system for all students, with additional for Muslims, they also provided classes for reading Al-Quran in Braille. A program called TEVET, conducted around 26 months, and the courses are up to the students to choose from. MAB courses are approved by *Jabatan Pembangunan Kemahiran* (JPK) or the Department of Skills Development where students are able to achieve *sijil kemahiran* (skill certificates) level 3 until level 4. There are freshly high school and A-level graduates who came here to pursue their studies after high school level. Those I've interviewed said many of them went to MAB for short courses while waiting for their *Sijil Pelajaran Malaysia* (SPM) results.

SPM is the biggest final exam for high school students in Malaysia. For the employment placement service in MAB, many students preferred to be a teacher, because it is a fixed and more secure option for them. For example, if they were to place in a business company, the chances of them being relocated to other departments or other partnering companies is high, making it difficult for them to get used to the new environment. Other than that, it is also due to the low demand for visually impaired teachers. There is also a program called Community-based Rehabilitation (CBR) where the officers will personally go to the student's houses for their lessons. This is due to some students who are already married or elderly who aren't able to move around without assistance. Other services include the library, Braille publication unit (eg. Braille textbooks) as well as technology like Braille watch. The senior citizens, they can come back and managed activities to inspire the younger ones as well as to keep the relations between them. The services are not only limited to the visually impaired, they are also provided services for the deaf-blind community. They are working very closely with Tun Hussein Onn National Eye Hospital and the doctors would frequently visit the premises to conduct regular check-ups. MAB doesn't operate according to the members' system, where the students need to have a membership to join the courses. They decided not to use that kind of membership because they offer help to ALL who came through the door. "We try to help them from womb to tomb," said Mrs. Sumitha, the senior manager of the research and development unit of MAB. These words strung my heart since they sound very reassuring and comforting for those who are in need of help. If we were to look at the statistics, many people choose the one in Kuala Lumpur as oppose to other places. Since in KL, there are more job opportunities, social structures, and easy access for maneuvering. Most are aged around 18-50. Although, these numbers aren't accurate due to government poor tracking for those who are considered to be visually impaired. The line between diagnosing children for blind or deaf is very tangible. Thus, the lack of information and difficulty for MAB to conduct any activities for the blind-deaf community had made it impossible to keep track of the OKU community in Malaysia. They wish for the government to better provide for this community in the future. After around 45 minutes of conversation with them, I have learned so much about the community from the constitutional perspective. Even so, regretfully, they had declined my request to enter class with their students due to the Covid-19 situation. However, they did direct me to Mr. F, an ex-student of MAB, currently a government officer in a public university.

On 11th April 2021, I met Azri (a pseudonym for the sake of privacy) at KL Sentral around 10:30 am. I was nervous. After all, I don't want to offend the visually impaired community because I believe I used an offensive word during my visit to MAB. When he arrived at the designated stop, after I had embarrassingly mistaken someone else who was also visually impaired and wore the same color shirt as Azri was wearing (he had told me on the phone), we were finally able to meet. I once watched a Youtube video about an interview with multiple visually impaired individuals answering questions about annoying things that happened to them. I remembered one of them said, if a sighted person wants to help them, I should offer them my shoulder or arm for them to hold onto instead of me grabbing them. Thanks to that video, I asked Azri, which one of the alternatives he's most comfortable with. He chose to hold onto my right shoulder instead of my arm to show respect to me as a woman. Subconsciously I took it upon myself to become his eyes at that point, so I kept pointing out everything around us like; "we need to turn right to get to McDonald's. We should turn right in 3, 2, 1, turn" and "someone is coming towards us and will be very close to your right in, 3, 2, 1, dodge". Truth be told, I've never done this before and I was very relieved that the journey from the terminal gate to the fast-food restaurant went by very smoothly. From Azri's experience, it started when he was 15, during his trial *Penilaian Menengah Rendah* (PMR) exam which leads to his failure. PMR was Malaysian big exam for middle school students at Form 3 level. It has been replaced with *Pentaksiran Tingkatan Tiga(3)* or (PT3) in 2014. He said the words were shattered which makes it difficult to make out. For example the word *Ayam*, he was only able to make out the A and M. Y and A becomes "*Pecah*" or shattered. I wondered why he didn't tell anyone when it happened but I would suspect it's due to the confusion and fear that rendered him lost of what to do hence he just kept quiet for some time. The teachers found his failure very odd since he was an A student, which leads the teachers to discover his condition and made alternatives for him to take the PMR exam. His condition wasn't hereditary, however, his brother also has the same condition but not as bad as his. He then went to SMK Pendidikan Khas Setapak, Kuala Lumpur for Form 4 and 5, where he depended on the magnifier tool supplied by the school because at this time he didn't learn Braille. Then at St. John for his form 6, and only then he started to use the Braille system because the magnifying tools weren't enough for all the students. He learned Braille because his other friends needed them more. (It comes to my attention that many visually

impaired usually take form 6 rather than diploma) it was a struggle to learn Braille because while he was learning the system, the classes were still going on. That made it very difficult for him to adjust however he managed because, in these hard times, he said all of his senses become sensitive. The survival instinct kicks in. When he comes home to Perak, people would talk loudly that hurts him as a person, which results in him not going out whenever he went home. In his words, he said "*Bila aku balik kampung, aku mati akal. Sebab aku tak boleh nak buat apa*" which translates to "When I went back [home], I would be at a loss because it is impossible for me to do anything" because the facilities aren't safe for the visually impaired. It's very different compared to KL due to the more open-mindedness towards the visually impaired; some people helped him and those just ignore him, and he prefers that [being ignored] rather than being talked down upon. The thing is, in terms of education system and facilities. It is very... disappointing, in my opinion. From what Azri said, even though he went to high schools that specifically for the disabled, there weren't even tactile in the school. The facilities were not adequate at all. And they have to maneuver around the school themselves and get used to it by memorizing. He, to this day, has no idea if he's using the cane properly. It is more on trial and error based on his seniors and his own experiences.

Mr. F, an administrative officer at the Students with Disability Management Unit at a public university, also started when he was a teen at 14 years old when his vision suddenly turned black during recess time at school. After almost a month at the Hospital Sungai Petani, Kedah, the doctors decided to just let him go home and told him to register as a PWD cardholder and admit him into a special education school. He never knew what his condition was and it had become worse due to him not receiving any treatment that leads his vision to turn dark permanently. Of course, at first, it was very hard to accept, but he had adapted and lived a normal life. Since he was a student at the university he is working at, I asked about the improvement compared throughout the years, he said, to compare as a whole is very subjective because even he can't say where in Malaysia has the best facilities for the visually impaired, even for the PWD community as a whole. So going back to the university, the improvements are there. He compared it to this, he said, ten years ago, students with the visually impaired have this saying, "*kalau kau tak jatuh longkang, kau takkan graduate*" which translates to "If you never

fell into a ditch, you would never graduate” that means the incidents happened so frequently. The current students had lesser incidents, even none to some. So here, we can say they are an evolution of facilities, of course, there’s always room for improvements. In terms of knowledge, it’s not enough when someone just knows about the disabled community. It’s different than those who have PWD children, or PWD siblings, or even in a close-knit community that takes care of the disabled. It’s different between those who only know and those who embrace the PWD community. He said something during the interview that stuck to me, “*Untuk bercakap tentang OKU (orang kurang upaya), memang tak mencukupi sekadar dengan pengetahuan dan kesedaran. Kita kena ada jiwa*” which roughly translate to “In order for us to talk about PWD, it is not enough with only awareness. We need soul” An example of this statement is the university’s shuttle driver that commutes the disabled student’s dormitory to their classes with a deep understanding and *menjiwai* or passion with their duties. When they drop the students off, they would need to let down the tramp, a hydraulic machine for students with wheelchairs. If it rains, what would they do to make the journey more comfortable? So if they are truly *menjiwai* their role, they would think the students would need to use both hands to maneuver their wheelchair, so this prompts them to take the initiatives to hold the umbrella for the said student. And if a visually impaired student is not used to the pit stop, they should get out and lead the students to safety. This is not a typical driver job where you just drop people off at a stop; they need to have this *jiwa* for this particular job that caters to the need of the disabled students. From this interview, I can see the initiatives taken by the department and can see why many disabled students choose this institution as their main choice, as they feel much more secured to pursue their studies safely.

Irfan’s and Rajesh’s (pseudonym for the sake of privacy) experiences in school are similar as they went to SMK Pendidikan Khas Setapak for their high school education, the same as Azri. It would turn out, Azri is their friend and senior. Irfan had similar experiences as Azri’s and Mr. F’s because all of them started to lose their vision in their teen. As a born visually impaired child, Rajesh had always been a frequent visitor to Tun Hussein Onn National Eye Hospital up until he was 9 years old. Even though he can only see a bit of shadow in his right eye, he can still see 25% vision on his left eye; colors, big shapes, and short distances. He started

his kindergarten in MAB where he learned Braille. In Sekolah Kebangsaan Sungai Kantan (SKSK), Kajang, has a program called Integrated Special Child Education Programme or Program Pendidikan Khas Integrasi (PPKI) where he went for primary level. He doesn't mingle with the sighted students when he was younger compared to when he was in Form 6 at St. John Institution. In St. John, the students warmed up to his condition then lead them to be more curious to know about the visually impaired. Some tried to learn Braille and helped Rajesh in taking notes when the teacher wrote on the board or when the school issued a new textbook with no Braille version. Even though he can use the screen reader² on his laptop to do his homework, the student assistants or *pembantu pengurusan murid* still encourages the students to use Braille as their homework medium. The assistants will then transcript to regular text and will submit the homework to the respective teachers. It would be easier and quicker to use a laptop to do their work, but Rishan guessed the assistants want them to get used to Braille.

Food For Thought

As Mr. F said, "*Untuk bercakap tentang OKU, memang tak mencukupi sekadar dengan pengetahuan dan kesedaran. Kita kena ada jiwa*". An example of his statement, when a common misconception is, the disabled people are overly sensitive. Nobody likes to be approached unannounced or manhandled. If we were in the situation, we would feel uncomfortable too. Especially since they can't see who the people near them are; this triggers a very high alert situation. So, to say that they're too sensitive is not fair. If a sighted person wants to help a disabled person, the right and logical thing to do is to only ask. Simply ask, of course, with manners; just like when we approach anyone in public. Many feel they're walking on eggshells when it comes to approaching a disabled. I believe this is because there's a wall between the able-bodied and the disabled. Subconsciously, since there is a clear physical difference, many classified it as an alien thing which in turn makes them unable to think rationally and logically. If the disabled refuse the help, there is no need for the able-bodied to feel offended or ashamed. I think it's a different story if we are to look into the same situation but different subjects. If both of the subjects are able-bodied, person A is offering help to person B and B refuses, it would be

the end of it. Person A would move on without making it a fuss. However, it's different when it comes to the disabled. In Mr. F's experience in working as a dishwasher before his job in the public university, the employers admitted he didn't intend to employ him because he feels sympathy towards him. Mr. F said he was just like any other person who wants to work to feed himself. Yes, having a disability is difficult, but with this mentality of over-sympathies, it would make the disabled very hard to obtain employment. They also want to work. It can give them a sense of purpose and the ability to sustain their life. The difference experience in terms of culture in Brunei is how they view PWD people as a person that need to help to a point they don't have to do anything anymore because their living expenses are all been taken care of. However, in Japan, they would be angry with those who help the PWD people because you need to ask them first, because, in their eyes, PWD people are regular people, and needed to be treated equally. If someone helps them without asking, it means that person is degrading the disabled person.

I also had a casual discussion with Azri and Rajesh about what are the things we can do to nurture our future generations about the disabled community. According to Azri's, Irfan's, and Mr. F's experience as kampong children with disabilities, they were very shocked and lost since there isn't much exposure to it; they only had seen the community through television shows. I believe this is because the disabled migrated to the city to have the accessibility for comfort as a disabled. This in turn separates them from their families and many aren't keen to go back to their birth-states as there are close to no chances for employment. For starters, we can have the exposure of different communities, including the PWD community through Civics Education and Nationalism (*Pendidikan Sivik dan Kewarganegaraan*) subject. During our discussion in May, I wasn't aware of the current modules for the said class. After future research, I found out that there is a module, particularly about the OKU community.

NILAI TERAS	PENDIDIKAN SIVIK					
	TAJUK	KONTEKS	LITERASI SIVIK			AMALI SIVIK
			Pengetahuan Kewarganegaraan (Pengetahuan)	Karakter/ Sikap Kewarganegaraan (Sosioemosi)	Keterampilan Kewarganegaraan (Tindakan)	Contoh Aktiviti/ Program
HORMAT-MENGHORMATI	Hormat Kepada Keperibadian Individu	Diri, Keluarga, Sekolah, Masyarakat, Negara dan Global	<ul style="list-style-type: none"> Menyenaraikan kategori Orang Kurang Upaya (OKU) Menjelaskan kepentingan menghormati keperibadian individu Menerangkan kepentingan kemudahan untuk kesejahteraan golongan kurang bernasib baik dan OKU Mengenal pasti kaedah membantu OKU 	<ul style="list-style-type: none"> Mengekspresikan perasaan prihatin akan isu-isu yang berkaitan dengan OKU Menzahirkan empati terhadap golongan OKU dan golongan kurang bernasib baik 	<ul style="list-style-type: none"> Bekerjasama dengan pelbagai pihak untuk kesejahteraan golongan kurang bernasib baik dan OKU Membantu golongan OKU daripada pelbagai cara Peka terhadap perbezaan individu 	<p>Aktiviti PdP</p> <ul style="list-style-type: none"> Aktiviti PAK21 tentang kepentingan kemudahan untuk OKU Menonton video lagu "Namunku Punya Hati" dan pembentangan hasil kumpulan <p>Aktiviti Kokurikulum</p> <ul style="list-style-type: none"> Mengenali simbol dan kemudahan untuk MBK Mewujudkan sekolah mesra MBK <p>Program Sekolah</p> <ul style="list-style-type: none"> Khidmat masyarakat di Pusat Latihan Perindustrian dan Pemulihan (PLPP) Kempen #santuni OKU Bual bicara tokoh OKU yang berjaya

Screen captured from *Modul Exemplar Pendidikan Sivik Sekolah Menengah Rendah* pdf booklet.

Source: <http://infomalay12.blogspot.com/2019/07/muat-turun-manual-exemplar-pendidikan.html>

From here, it would be easier to implement inclusive programs in schools throughout the country. As stated in Malaysiakini newspaper post published in 2019, saying that inclusive programs have shown positive outcomes for both children with and without disabilities. Children with disabilities in inclusive programs perform better academically, form positive peer relationships leading to better socialization, and faced fewer behavioral incidents than being in segregated classrooms. Children without disabilities can obtain effective communication with all peers, understanding and not afraid of human differences, able to adapt to behavioral differences, reduce stigmatization and prejudice, discrimination, nurture respect for all peers.

Contemplation and Reflexivity

Azri is in his practical training, working on a project in Social Welfare Department (JKM) to give insights about hospitals adequate training dealing with PWD and proper facilities. He said his colleagues were very shocked to see him on the premises as it is not common for the visually impaired to choose the medical field as their research paper. He said it is more personal to him to fight the stigma to prove that he indeed belongs there despite his condition. Although, the resolution isn't without a price as he struggled tremendously due to the lack of facilities for the visually impaired in the hospitals. Ibarahim (2011) says in 2010, there's only 313, 685 registered PWD in Malaysia which starkly differs from the United Nations estimation of 2.8 million or 10% of the total population of 28 million. According to Islam (2014), PWD is the nation's most likely to be taken lightly, even taken for granted in all aspects of life, in particular with this research; the challenges to facilitate due to the complexity of healthcare buildings. According to (Kamaruzzaman et al., 2016) finds that the respondents in hospitals located in Perak are "aware" of the lack of facilities provided by the hospitals. Even though they abide by Uniform Building By-Laws (UBBL), there are still many improvements that need to make to ensure the largest minority in the country have accessibility to healthcare with comfort.

An upsetting experience Rajesh shared with me happened on his way to St. Nicholas for his IT training while trying to locate his Grab car. It was raining heavily at the time that makes it difficult for him to hear his surroundings and to locate the location of the GrabCar waiting area. Someone approached him and asked multiple questions that made Rajesh feel uneasy. As if the man was attacking him for being blind and able to move around without assistance. Questions like "Are you blind?" "How did you book the Grab?" "Where are you going?" "What are you going to do there?" "What are you doing with your life?" These questions were indicating he didn't believe to see a visually impaired man able to be independent. I would say this may have been connected to the stigma that the visually impaired are up to no good as many are spotted panhandling or selling tissues around city areas. Also, the stigmas of the disabled are not capable of being independent. Hence, truly disabled aren't capable to move around on their own,

meaning this seemingly visually impaired man [Rajesh] is not a PWD, meaning he is up to no good. Other situations that Rajesh frequently experiences are the public handing him cash without notice and left the confusing man wondering and attempted to return the cash. He said, as a person with integrity, it's hard to accept money from strangers because it made him feel incompetent and wondering "Do I seem that pathetic?" The possibility is, as I mentioned before, the view of the visually impaired panhandling and selling tissues are commonly associated together. This mentality is very upsetting and can be detrimental to the disabled community's empowerment. Of course, this is a big world, and bad apples are everywhere in the community. However, if awareness and knowledge about the community are well embedded into our mentality, these kinds of situations can be avoided.

References

Ibrahim, Z. (2011). Most Handicapped People Not Yet Registered With JKM. *Inclusive Design for Malaysia*. <http://inclusivedesign.wordpress.com>

Islam, M. (2014). Rights of the People with Disabilities and Social Exclusion in Malaysia. *International Journal of Social Science and Humanity*, 5(2), pp. 171-177.

Malaysian Association for the Blind. Profile.

Retrieve from <https://mab.org.my/maborg/about/profile.html>

National Early Childhood Intervention Council. 2019. Make Education for Special Needs

Children Inclusive, Not Integrative. Retrieved from

<https://www.malaysiakini.com/news/458869>