

DISABILITY RESEARCH PRODUCTION IN MALAYSIA: A CALL FOR CRITICAL DISCUSSION AND EMANCIPATORY PRAXIS

Muhamad Nadhir Abdul Nasir
Faculty of Arts & Social Sciences
University of Malaya, 50603 Kuala Lumpur, Malaysia
E-mail: anndh91@gmail.com

Rosila Bee Mohd Hussain, Ph.D
Faculty of Arts & Social Sciences
University of Malaya, 50603 Kuala Lumpur, Malaysia
E-mail: rosila_bee@um.edu.my

ABSTRACT

This paper presents our cumulated work on disability research production in Malaysia from 2016 until 2018. We divide our findings into three parts; policy-legal analysis, survey analysis and interview with two local activists. For policy-legal analysis, we extract data from government policy documents and legislation, namely the Persons with Disabilities Act 2008, the Policy for Persons with Disabilities 2007 and the Action Plan for Persons with Disabilities 2016-2022. For our second and third data source, we conduct an online survey which we receive the response from 46 respondents and conduct a semi-structural interview with two local visually impaired activists. From the policy point of view, there is a mechanism to promote and monitor disability research discourse in Malaysia. But, there are few gaps that must be addressed. Even though our survey respondents and two local activists recognize the importance and benefits of disability research, there are growing concerns with regards to local disability research implementation. The most pressing issue is the failure of local disability research in bringing change or producing impact to better the lives of a disabled community. We also discuss ethical issues, research method adjustment and ways to engage local disabled sample for research purposes. Findings also show that there are four main factors for a disabled individual to take part in research: (a) Research topic; (b) Research impact; (c) Suitability of time and meeting place; and, (d) Token. We recommend the government to establish a research center dedicated to disability research in Malaysia and the development of general ethical guidelines for local uses. We also underline the limitations of our current work and put forth some future paths in researching this topic.

Keywords: Disabled sample, disability research, research impact, methodology, emancipation.

Introduction

The purpose of social research is to explore, give a clear picture and explain the causes of a social phenomenon in a society (Babbie 2011, pp. 18-20). However, social research paradigm that focuses solely on the production of new knowledge is no longer sufficient in today's world since most of the recent social phenomenon, especially relating to poverty, inequality and injustice need to be solved systematically through scientific and evidence-based solutions. This is because inequality which produces social differentiation that leads to social problems and injustice must be eradicated (Kntayya 2000, p. 10). The keyword here is emancipation. Social scientists do not only have obligation to produce new knowledge in their respective fields but in fact, they must also uphold the goal of liberation through their work for human advancement.

Emancipatory paradigm resonates nicely with the endeavour of disabled researchers and activists in disability research. Doing disability research is not only to offer a platform for critical theoretical discussions, instead to present disability issues as both intellectual and political agenda to bring the emancipation of disabled persons into a reality. In Malaysia, local academicians and students have shown interests in disability issues and this continuing progress is undeniably a good sign. But, to the extent of our knowledge and observation, there is no research conducted to reflect on the impact of those studies, or at the very least to study local disabled community's perception towards local disability research.

This paper presents our cumulated work on disability research production in Malaysia, looking from the perspective of policy and legal, as well as from attitude and feedback of local disabled sample towards local disability research. We begin this paper with a discussion on past literature. Next, we explain our methodological framework. Afterword, we present the findings before concluding by addressing our work limitations and future paths for this topic.

Literature Review

Discussion on disability research production begins more than twenty years ago which can be seen in the work of prominent scholars such as Oliver (1992, 1997), Zarb (1992), Morris (1992), Barnes (1997), Barnes and Mercer (1997), Bury (1996, 1997), Shakespeare (1996, 1997) Rioux (1997), Priestley (1997), and Stone and Priestley (1996). The discussion on disability research production became more contentious with the introduction of the social model of disability and the promotion of emancipatory paradigm which aggressively promoted by Oliver (1992, 1997, 2002). In many years, emancipatory disability research has gone through many reflections, discussion, and criticism by many scholars (Barnes 2003; Barnes & Sheldon 2007; Barton 2005; Danieli & Woodhams 2005; Mercer 2004). The need for discussion on disability research production does not only to fulfill advance epistemological desire but also to bridge the gap between knowledge production and knowledge translation.

Shakespeare (2015, pp. 2-3) categorizes disability research into three main approaches and those are materialist, constructionist and critical realist. Materialist disability research focuses on the political impact of such work rather than on theoretical discussion. On the other hand, constructionist disability research debates on an advanced level of theoretical discussion but has little impact on emancipatory actions. As for the critical realist disability research, this group of researchers is more fascinated to the complex and complicated entanglement of different dimensions of a disability issue which requires critical debate and grounded in reality. In foreign countries, especially in the United States and the United Kingdom, we can see many compilations of disability research such as book edited by Morris (2006), Shakespeare (2015), Wappett and Arndt (2013a, 2013b), Kroll (2008) and many others. There are also scholarly work that assess the historical development or auditing the progress of disability research production in different countries such as in Norway (Tossebro 2013), Sweden (Soder 2013), Finland (Salovvita 2013), Denmark (Bengtsson & Bonfils 2013), Australia (Llewellyn 2014), and Southern African region (McKenzie, Mji & Gcaza 2014).

However, there are concerns amongst Disabled People's Organizations about the readiness of academic institutions to view them as equal in the framework of the social model of disability and human rights-based approach (Priestley, Waddington & Bessozi 2010). Kitchin (2000) also discusses many of the concern with regards to disability research production based on the opinion of persons with different types of impairment. In Kitchin's (2000) work, his respondents emphasize strongly for emancipatory and empowering research strategies, an involvement of disabled people as consultants and research partners and argue for exclusive research approach which disability research is conducted by them who are disabled themselves.

In Duckett and Pratt's (2001) work, their respondents emphasize the need to respect individuality, practical and action-oriented research as well as committed to emancipatory research agenda. In their research, they also discuss the way to increase the recruitment of visually impaired persons in research. As such, it is already passed the mandatory period for us Malaysian researchers, especially for those who committed to bringing the emancipatory research agenda in this country, to reflect on the impact of disability research so far to the lives of the local disabled community.

Methodology

In our effort to understand disability research production in Malaysia, we extract data from three sources; policies and legislation, feedback from an online survey and interviews with two local visually impaired activists. Firstly, we conduct a content analysis of three main government policies and legislation relating to disabled people. Those documents are Policy for Persons with Disabilities 2007, Persons with Disabilities Act 2008 and Action Plan for Persons with Disabilities 2016-2022. We use two keywords which are 'data' and 'research' in identifying and analysing those documents.

Secondly, we use a technique which we call 'blast technique' where we disseminate an online questionnaire through social media platforms, namely Facebook, WhatsApp, and email. After data collection period ends, we receive 48 responses. However, we have to reject two responses because there are two respondents who answer the survey twice. We develop the questionnaire using the Google Form platform. Survey questions are written in Malay language. Prior to uploading the survey, we ask a postgraduate student with visual impairment to assess the accessibility aspect of the survey. For the record, no changes are made to the survey after the assessment since the survey can be accessed using screen reader software. Then, we upload the questionnaire onto various Facebook groups joined by the first author. The online survey is disseminated twice. First, on 14 April 2017 and the second time is on 18 April 2017. The collection period ends on 11 May 2017.

Finally, we also conduct two rounds of interview with two local visually impaired activist. We pick the two informants purposively. Both informants, Rizq and Marty, hold a position in national-level blind people organization situated in Kuala Lumpur. They participated in a lot of research as a research participant and they too have the experience of conducting their own disability research amongst the blind community. Both Rizq and Marty also have a bachelor's degree and Master Degree from a local higher learning institution.

We do the first round of interview in January 2017, whereas the second round is between April and May 2017. We use a semi-structural interview schedule to guide the first interview session, whereas the second round is more unstructured. We conduct the interview sessions in Malay language. Thus, for the purpose of this paper, we try our best to translate our informants' quotes into English without changing the messages and meanings. We record all interview sessions and then transcribe them for analysis. We analyze the interview transcripts using thematic analysis method. We conduct the analysis process manually, without using any qualitative data analysis software such as ATLAS and NVIVO.

Discussion

In this section, we divide the discussion into three parts, based on the data sources which are policy-legal analysis, survey analysis and interviews with two local visually impaired activists.

Policy-legal analysis

Under section 9(1) of the Persons with Disabilities Act 2008, one of the functions of the National Council for Persons with Disabilities is to collect and collate data and information, as well to conduct or promote research relating to disabled Malaysians. Such function fits the National Council for Persons with Disabilities since this council is tasked with advising, proposing, coordinating and monitoring national policies and action plans regarding disabled people in Malaysia. However, it also sparks a few questions:

1. Do the council have the capacity, in terms of finance and human resource to fulfil such a function?

2. Do the government and the council recognize the importance and prioritize the implementation of disability research?

According to section 18 of the act, it is the duty of the government to provide sufficient fund to the council to fulfil its functions. Furthermore, the Department for the Development of Persons with Disabilities is required to assist the council to perform its functions under section 10. In principle, the council should possess autonomy and resources to conduct or at least nurture local disability research production.

To answer the second question above, we look at the Policy for Persons with Disabilities 2007, which is the basis for the Persons with Disabilities Act and the following action plans. Research and development is the twelfth area designated under the policy.

The policy underlines two main objectives:

1. To encourage research and development relating to disabled persons and disseminate research findings for improvement purposes; and,
2. To enhance the mechanism of coordination, implementation, monitoring, and evaluation of programs relating to disabled Malaysians.

On paper, the government and the council seem to recognize the importance of research, whereas in terms of prioritization is still questionable. Currently, there is an online database on disability research under the authority of the Institute of Public Health, known as the Clearinghouse for Research on Disability.

In the Action Plan for Persons with Disabilities 2016-2022, research and development are designated as eighth core strategy with the same objectives laid out in the policy mentioned above. The action plan lists out the following measures on research and development:

1. The establishment of database and information system relating to disabled people by the Ministry of Women, Family and Community Development;
2. Improvement of research directory system and social mapping relating to disabled persons by the Ministry of Education;
3. Encourage research production among academicians;
4. Dissemination of research findings through various medium by the Ministry of Education;
5. Funding provision for research by the Ministry of Science, Technology, and Innovation;
6. The establishment of an evaluator group through collaboration by the Ministry of Women, Family and Community Development; and,
7. The development of evaluation guideline and disabled people's well-being index.

Despite the long list of actions, they put in the action plan, we notice several key issues which they overlook. Those key issues are:

1. There is no mention of an effort to develop a national roadmap on disability research production with its priority areas;
2. There is no mention of an effort to develop general ethical guidelines for conducting disability research;
3. There is no mention of local higher learning institutions and research centers as collaborators in the plan; and,
4. There is no mention of an effort to institutionalize disability studies as one of the scientific fields.

Generally, to our understanding, the council as provided by the law has the duty to conduct or promote research in all aspects of disabled people's life. However, the act explicitly mentions research under section 36(2) which the government is required to conduct or take measures to cause survey, investigations, and research in order to prevent other occurrences of impairments. We wonder whether subconsciously the government, both at the time this act in the drafting stage and even today, still preoccupied with medical-oriented research on disability. From the analysis of local policies and legislation, Malaysia has the mechanism in place to nurture meaningful disability research production. However, several issues as listed above must not be overlooked by the government.

Survey analysis

From the respondents' feedback, only one respondent (2.2%) views disability research as not important compares to the remaining 45 respondents (97.8%) that have an opposite view. Based from 45 respondents' answers, we can summarize that disability research is important: (i) To nurture awareness and understanding among researchers and the public about disabled people's issues; (ii) To identify the needs of disabled people and solutions to their problems; (iii) To add to the knowledge about disabled people's issues; (iv) To provide reference for policy makers and service providers; (v) To contribute in the skill development among disabled people; and finally, (vi) To provide channel for disabled people to voice out their issues.

Looking at the six advantages of disability research pointed above, we can argue that disability research benefits at a personal level, community level, and institutional level. At the personal level, disability research can contribute as an opportunity for disabled individuals to gain skills and a space to express one's ideas and challenges. At the community level, disability research can raise awareness and positive attitude among the public by addressing the issues faced and capabilities possessed by disabled persons. Lastly, government and service providers as institutions in society can utilize the findings from disability research to formulate new policies, or to amend existing policies to include the needs of disabled people as well as to produce new services which are more accessible and equitable for this minority group.

Most of the findings in this subsection echo the same concerns in Kitchin's (2000) and Duckett and Pratt's (2001). First, the most frequent answer we receive from our respondents is there is no impact from the research conducted by researchers on disability issues. The frustration shared by the majority of our respondents can be seen almost in an exact answer such as:

”Research is just research without actions at the higher level”

Some respondents claim that research is only conducted to meet the meritocracy needs among the researcher. The following responses address this issue:

“The thing that makes me worry is the research is only conducted to fulfill their graduation requirement which the research findings just beautifully mentioned in the thesis but it is not practiced in daily lives”

“Research is conducted to complete the assignment in the higher learning institution. The research findings also do not bring impact to the development of disabled people as well to increase their life status”

Some of our respondents also concern about the risk to be exploited by researchers. We receive two response on this matter that describes this concern in short sentences: “Exploitation of disabled individuals or disabled group” and “For their utility”. Exploitation can happen due to several reasons. First, no proper guidance for the students who conduct research on the disabled group. Second, researchers do not consult with the disabled individuals or their organizations upon planning the research. Third, researchers fail to see disabled individuals and Disabled People’s Organizations as research partners and expert in their own issue. Two respondents point out excellent responses which can explain the exploitation by researchers. In their responses, they write:

“... certain research fails to take into account disability issues at the planning stage which causes the disabled people unable to participate effectively in the research. Lack of reference materials, lack of expertise in disability issues and lack of researchers’ involvement with the disabled community lead them only to do a superficial study”

“... researchers who do disability research may not have a full grasp on the issues of disabled people. The questions they ask sometimes make disabled people become doubt because most of them do not ask first and do not conduct a pilot test on the questions”

Besides that, concern about research ethics are also raised up by our informants that write such as “worry if they ask sensitive questions” and “As a person who is blind, I feel worried in the situation where the researcher takes picture or record a video without the respondent’s aware about it and without getting consent”. Ethical issues with regarding taking photo or video of research participants have been discussed abundantly (Devakumar, Brotherton, Halbert, Clarke, Prost & Hall 2013; Mji, Schneider, Vergunst & Swartz 2014) as well as other aspects of research ethics. Like choosing an accessible research design and method, equal attention must be given to research ethics.

A risk of misunderstanding among researchers becomes one of many concerns voiced out by our respondents. A respondent writes:

“My worries are, if the researchers are not from the disabled community, they may not understand the real problem happens among disabled people and may misinterpret it and then produce inaccurate research findings”

No information after data collection is another point of concern brought up by our respondents in the survey. One respondent write: “The concern is there is no update after the research has been done”. This may happen due to the fact that research findings sharing is not a common practice of local researchers and this can make the disabled individuals who participated in the research to feel that “they were left hanging” as well as they cannot use such research for their advocacy purposes.

One respondent also mentions the failure of the research to receive good responses from the disabled community. The respondent writes: “My concern is that the researcher does not receive the response for his or her research”. This point may be caused by the first point of concern, which is the failure of previous research to produce any form of impact or change into disabled people’s lives that lead them to scarce away whenever new researchers come to do disability research on their issues.

Finally, there are some respondents urge for the implementation of holistic disability research. One respondent concern about the lack of diversity in research topic by stating that: “The concern is that most of the research only focuses on physical development. Always research about public facilities and infrastructure. No progress in other aspects. Eventually, society only talks about that topic and feels that other aspects are not important for disabled people”. It is undeniable fact that different scholars have different research interests and research focus areas. One way to overcome this situation is through collaboration between non-disabled academicians and disabled academicians or Disabled People’s Organizations to identify relevant current topics to the disabled community.

Another respondent emphasizes that lack of holistic research lead to an ineffective solution. The respondent writes: “Research is not holistic and comprehensive which cause the solution cannot be used”. Cross-disciplinary disability research has gain popularity in recent years in disability studies. This is because cross-disciplinary disability research can offer a comprehensive and holistic look into the problem or the phenomenon. Undoubtedly, further research is needed to investigate local praxis on multidisciplinary disability research which may foreshadow the relationships between the academia and activism sector.

Interviews with two local visually impaired activists

Both of our informants have a positive view of the benefits of disability research. For Marty, disability research is important to provide evidence to the government when disabled activists and Disabled People’s Organizations are lobbying for a policy or programme development.

"I think we need to do research on the issues related to the disabled people. This is because when we do the discussion or lobbying the government to set up a particular policy or program, the questions they ask us are what is the target,

What is the impact and so on ..." (Marty, 10 January 2017)

Marty also adds that disability research can also be used as an evaluation tool to improve services for the visually impaired community.

"We have to do research, we have to evaluate whether the services we provide are still needed or not. That's the reason why we have to conduct research ... if we offer unnecessary service, it just a waste. And another reason is to formulate the direction of the service trends today." (Marty, 10 January 2017)

For Rizq, the benefit of disability research can be seen in terms of technology development.

"It's important. Disability [issues] actually need us to do a lot of research and development. [For example] the study on Quran braille panel ... They produced the product, and we test it. That's good..." (Rizq, 10 January 2017)

Although they recognize the benefits of disability research, both Rizq and Marty are worried about previous research are not translated into meaningful actions.

"I think many people are doing research. But how many or how much research is used as a guide to convince the government that I am not sure. Research is just research and it is not used. We have to do research and then we use [the outcome of the study] for certain purposes." (Marty, 10 January 2017).

"It seems, I feel many are just as project paper or academic exercise or thesis for a Ph.D. [or] master only. For future use, I don't see it." (Rizq, 10 January 2017)

Marty argues the current practice of research production may be caused by a couple of reasons. He explains:

"I think we cannot blame them because they have no motivation to carry on. It's different if it's science, innovation, and so on ... It is possible to commercialize... But in our issues [disability issues] maybe they have no motivation to move forward so just keep it..." (Marty, 20 April 2017)

The concern voiced out by Rizq and Marty echoes the same findings in previous work (Kitchin 2000). It seems most of the local disability research, if not all, are still dominated by traditional research paradigm which can make disabled Malaysians community become more frustrated which then can lead them to distant or distrust academicians' role in bringing change into their lives. Rizq highlights the risk of being exploited by researchers as follows:

"I think yes. Because sometimes they want to raise their position ... but most important is the result after that, there is nothing. When there is no result, so there is no effect. Therefore, we feel like being manipulated." (Rizq, 18 May 2017)

For Marty, he acknowledges and understands the academic requirement.

"Exploitation, I think that word is too harsh. I think their [researchers and students] intention are not to exploit, but their intention to get a degree... so I think their intention is not more than that. Most of them just come here to complete their thesis. After that, the study will be kept in the library." (Marty, 20 April 2017)

With regards to research ethics, from the interviews with our informants, there is no need to develop a new set of research ethics when involving visually impaired sample in research. However, they emphasized that researchers must pay more attention in terms of interaction with their sample. Researchers must first understand their sample group as Rizq illustrates in his response below:

"Most important are [whether] the researchers understand well and correctly or not about their disabled sample. Sometimes they conduct the research, they do not fully understand. So, they need to understand." (Rizq, 10 January 2017)

Hence, Rizq suggests that researchers must refer to the expert in the field to familiarize themselves about the disabled community.

"I think... they may need to refer to the relevant expert. For example, the disabled person. I think the disabled person is better." (Rizq, 10 January 2017)

Researchers should also ensure that their sample is fully aware and able to access the information about the study. Research information must be made accessible to the visually impaired sample.

"The research information should be recorded in the survey form. So, if it's not in the accessible format, so depends on the researchers whether they want to read it or not, or read it half the way, or read it entirely. So we don't have the way to really know whether they explain it all or not... because we depend on them. ... it depends on the respondents' education level as well. If the respondents' education level is not high, so they may not so interest to ask more detail about the research purpose and so on. If they are educated, they will ask." (Marty, 10 January 2017)

As researchers, we must uphold our ethical responsibilities. One of it is to make sure that our research participants receive all necessary information about the research project. Another crucial detail that should be considered by researchers is terminology used when they are interacting with the visually impaired sample. Rizq explains:

“... What we need to be paid attention is in terms of terminology. ... researchers may ask the disabled persons what is the appropriate terms that they can use to refer to their impairment. Maybe that person just becomes visually impaired and somewhat sensitive with the word blind for example ... he wants more suitable terminology ... ask the participants which terminology is more appropriate to use to refer to their impairment.” (Rizq, 10 January 2017)

Researchers must also inform their research participants during the process of signing the respondent agreement form. Rizq highlights this point by saying:

“... for signature, maybe they can sign it. But they should tell us that they want to sign for us... then [suddenly] OK. they signed for us without our permission...” (Rizq, 10 January 2017)

Communication is not only important during the data collection process, but also the researchers must practice continuous communication after the research project is completed. Unfortunately, according to our informants, researchers never share their findings or research report with the informants even though they ask for it.

“... I always ask all the researchers to send a copy of their research report to us when they finish. But until now, we don't receive any copy of the research...” (Rizq, 10 January 2017)

“When they came, we told them to send a copy of their research report to us. But unfortunately, no ... They promise to send us a report and so on. But nothing. We don't want to affect their research... we know that they will get a degree and so on. We don't want to complain...” (Marty, 10 January 2017)

It seems that it is uncommon for researchers to share their findings with their research participants and Disabled People's Organizations. This can further the gap between research and social change and between the academia and the disabled community in Malaysia. Good and quality relationships between the researchers and the researched serve as impetus to meaningful research production for both parties. To this end, researchers must build a good relationship with their targeted research group prior to data collection and even when engaging the sample.

“Researchers always come and straightly do their interviews, there is no relationship... maybe one of the causes... is their perception. It depends on the researchers' perception ... I feel better if they can evaluate, give a broad perspective on disabled people. Sometimes they come here with their own perception...” (Rizq, 10 January 2017)

It is also evident that university students and academicians never come to consult them on the proper research implementation. On this point, Marty shares:

“... no. They come; they straight do their interviews. They don't get any consult. Maybe they are clever enough.” (Marty, 10 January 2017)

Instead, the common practice is that the researcher will come to their organizations and ask for a certain number of respondents. Both Marty and Rizq face some form of a dilemma when this happens.

“The researchers like to meet us, oh, I want 20 respondents. Usually, we will provide the respondent for them. So I think the researchers have to find for themselves... Because if they ask us to provide the respondents, we know many blind people... so I think the respondent selection is sometimes bias. Because we know that people have more or less similar thoughts to us so we will provide people who can give a positive response to the topic and so on. So I think sometimes it would be better if the researchers select randomly so that they can get a more sincere answer.” (Marty, 10 January 2017)

“Many of them are university students, they said that they want to find 50 respondents. ... It's difficult for us to find [the respondents] because of the cooperation from the blind people... Not everyone wants to cooperate. Unless we say that they can get money if you help them... many people will be interested. But it is no longer voluntary...” (Rizq, 10 January 2017)

Building a good relationship with the targeted research participants prior to data collection gives several advantages to researchers. The researcher can gain basic understanding and knowledge on how to communicate effectively with their sample when they spend some time interacting with them.

“... they have to find blind people ... or any category of disabled people that they are targeting in their research... interview first, get the information, how to communicate. We can go meet the respondents, visit their house first... maybe we can get a little bit of knowledge about the respondents... maybe meet them at least once or twice... if it involves the NGO or people, they must have a procedure letter and so on. I think it's better if we meet the respondents in a convenient place such as their house...” (Rizq, 10 January 2017)

Another advantage of building a good relationship with research participants can nurture a sense of comfort and trust between the researcher and the researched. This will increase the quality of information gained by the researcher in their study.

“If both are comfortable, it’s easy for us to do the research... the study will be more sincere. If the respondent believes the researcher, the answers that he would share maybe more sincere.” (Marty, 10 January 2017)

When collecting data, there is also a need to adjust the way we use certain methods. First, when using a questionnaire, pilot testing is crucial to make sure the items in the questionnaire are suitable to the context of disabled people. Rizq shares his frustration about the researchers who do not conduct pilot testing for their instruments.

“They just copy paste what they have, maybe those questions do not fit the disabled people. They have to modify it actually ... need to fit it to the disabled people [context]. Not general questions... they need to refer to a certain person. They need to do a pilot test first. Meet and discuss with us first. I want to do this research so can you give me a suggestion about the examples of questions. ... they give us an example of the question, we check ... then they can start the research. That is better.” (Rizq, 10 January 2017)

In addition, researchers who use questionnaire must prepare different format of the questionnaire form based on the needs of visually impaired respondents.

“... most of the researchers do not provide survey form in an accessible format for the blind people. So, the researchers or their research assistant will help us to read. And one more thing, they don’t provide us [on the information on] how we [should] respond. So, if we ask them to help us to write then our secrecy has been contaminated. ... or the things we want to convey may differ from what they write. I think they should give us options whether we want to do it using a computer or braille. I think it is necessary. Because some of our friends prefer to read in braille and we have to give them option too when they respond. Whether they want to write using a computer or braille.” (Marty, 10 January 2017)

Rizq, on the other hand, suggests that researchers can assist directly their respondents by asking the question and selecting the options according to the respondent’s response.

“It would be better if the researchers do a direct interview with the respondents. So, we can get the data straight. If the researchers expect the post system, email... maybe not everyone willing to cooperate to fill up the form.” (Rizq, 10 January 2017)

The key here is for the researchers to know their sample and their needs as Marty illustrates below:

“They have to understand their sample first. ... They have to understand maybe most of their sample, first, whether they can read or you as a researcher help them to read. Whether they can fill up the form on their own or you as a researcher assist them to fill up the form. Maybe you need to have many research assistants and so on. In terms of language, whether your sample understands Malay or you need to translate it into English and so on. We need to know. And another one that I think very important is accessibility. Maybe they are reluctant to become the sample due to the mobility problem. Maybe they can not come to our place and so on. So if they can not come to our place, the researcher should go and find them.” (Marty, 10 January 2017)

For researchers who employ focus group discussion, it is imperative for them to know how to communicate effectively with visually impaired people in a group setting.

“... have to call the respondents ... then they will respond. So, that’s the thing we have to do. If not, you will get... those who are talkative, will dominate... So, we have to try to balance it. It is important for the researchers to be able to memorize the names of everyone involved in the focus group discussion. Sometimes we also have to make the FGD questions in a readable form. It’s better... or a guideline ... question or point of discussion... and sometimes maybe we make a note... we are blind, can’t write... so, you as notetaker should always read so that they [blind members] can recall ... what things have been written. ... it’s better if there is a brailer.” (Marty, 10 January 2017)

On this point, Rizq adds:

“I think if focus group [discussion], it depends on the researchers’ skills... how to communicate, name the person that you want to ask. If they [the researchers] use non-verbal communication not everyone can understand. It’s good to have the guideline questions in braille [too]. It depends on the audience... If the participant can not read braille, it’s useless if we provide in the braille form. Follow their needs. But now they also can send in an audio form such as WhatsApp audio...” (Rizq, 10 January 2017)

During the interview, we also ask about the factors that influence the participation of visually impaired individuals into research. The first factor is research impact. Failure to bring change into their lives affects their motivation to take part in research.

“...people always come to do research with them, they may feel fed up to help because, in the end, there is no result. The researchers should be aware of this matter...” (Rizq, 10 January 2017)

“First, in their opinion, this research only helps the researchers. There is no outcome from the research. So, wasting their time. Or the researchers just want to use them. So, if we really conduct the research and use the data that we have to help

the disabled people like lobbying policy maker, or we introduce new service and so on, so when the disabled people see the result of their involvement, then they are interested to participate. ... Because they have been involved in many research so they feel fed up.” (Marty, 10 January 2017)

As Widom and Czaja (2005) suggest, there is a need for researchers to carefully tackle emotional reaction, the costs and benefits of participation among research participants. Next, both informants also advise researchers to find a suitable time and place to meet their research participants.

“... Maybe it’s difficult for them to come to one place. Maybe it’s too far. In terms of time, maybe the time is not right. Usually on weekdays, for those who work they will go to work. On weekends they want to rest. So ... maybe they are not interested to participate...” (Marty, 10 January 2017)

“Maybe we have to think where we want to do the interview for those disabled people who are working... it means that we have to find the right time for interviewing them... Maybe they are busy and so on. ... communicate more. The first step is to build the relationship... after that, find the right time to get them involved with the interview.” (Rizq, 10 January 2017)

As Rizq suggests, through a good relationship with targeted research group will enable the researcher to negotiate the appropriate time and location for data collection purposes. The third factor is the research topic. According to Rizq and Marty, visually impaired people will participate in a research that is relevant to them.

“One more thing is the issue of whether the research topic suits the disabled samples or not. They maybe feel worried if the research involves their employers... Sometimes the issue involving employers cause them to be afraid of confidentiality, such issues may have an impact on their involvement.” (Rizq, 10 January 2017)

“... Maybe the disabled people are not interested in that topic. Not their interest. So, if I’m not interested in that issue I’m lazy to get involved.” (Marty, 10 January 2017)

Lastly, Rizq points out token giving can also influence visually impaired individuals to take part in a study. He explains:

“But I think another attraction is in terms of a token. We can’t deny it... It’s a good idea if we can give the blind people something that might encourage them to participate in the research. But ... the token should not be mentioned to avoid [conflict of] interest... [besides that] the benefit in terms of knowing how to do research they will learn because they are involved with research... So, indirectly they learn how to do research.” (Rizq, 10 January 2017)

In Kidney and McDonald’s (2014) work, they develop a guiding instrument in engaging sample with learning disabilities to ensure their participation and accessibility in research process. In the instrument, giving incentives to the research participants is important to increase research participants’ engagement and participation among other aspects such as giving sufficient break time during data collection and diversifying data collection methods. Giving out token to research participants may have its shortcomings. However, we cannot deny that token symbolizes one’s appreciation for others. Taking lessons from what Rizq said above, incentive or token can be in a form of material or something worthwhile for the research participants. On this point, researchers have to be mindful and also thoughtful in managing reciprocal relationships between them and their research participants.

Conclusion and Recommendations

On paper, there is a mechanism to promote and monitor local disability research production, especially in terms of spearheading national-level data collection, funding, research compilation, and coordination. However, we highlight few gaps such as no clear national roadmap for disability research production, adoption of general ethical guidelines and institutionalization of disability studies. Meanwhile, findings from the online survey and interviews show there is a growing concern about local disability research implementation. Our sample frequently raises up their concern of the failure of local disability research in bringing positive impact in the lives of the local disabled community. Our sample also put a strong emphasis on research ethics, an appropriate way to engage disabled sample and communication after research.

We are aware of the limitations that our present work has. Findings in this paper must not be generalized due to its small sample size and highly contextualized. It is imperative to conduct further research on this topic. One future path is to study epistemic consciousness among Malaysian government agencies and service providers, including the leaders of local Disabled People’s Organizations and its effects on local disability research production. Besides that, there is also a need to research local ontology and epistemology on disability. This question is important and directly influence the principle and praxis of local disability research production.

Looking at the Malaysian government’s policies, we strongly believe that there should be a specialized research center on disability issues. This specially dedicated research center can act as a one-stop center for all research-related activities such as research compilation and coordination besides responsible to develop meaningful products such as government policies, initiatives, and legislative drafts. Currently, the present government through their manifesto wants to establish disability policy research center under the Social Institute of Malaysia. As of today, we have not heard any news on its progress. Furthermore, the government must also develop and publicize general ethical guidelines on disability research conduct for local uses.

References

- Babbie, E. (2011). *Introduction to social research*, 5th ed. USA: Wadsworth, Cengage Learning.
- Barnes, C. (2003). What a difference a decade makes: Reflections on doing 'emancipatory' disability research. *Disability & Society*, 18(1), 3-17.
- Barnes, C. (1997). Disability and the myth of the independent researcher. In Barton, L., & Oliver, M. (Eds.), *'Disability studies: Past present and future'* (pp. 239-243). Leeds: The Disability Press.
- Barnes, C., & Mercer, G. (1997). Breaking the mould? An introduction to doing disability research. In Barnes, C., & Mercer, G. (eds.), *'Doing disability research'* (pp. 1-14). Leeds, The Disability Press.
- Barnes, C., & Sheldon, A. (2007) 'Emancipatory' disability research and special educational needs. In Florian L. (ed.), *The Sage handbook of special education* (pp. 233-246). London: Sage.
- Barton, L. (2005). Emancipatory research and disabled people: Some observations and questions. *Educational Review*, 57(3), 317-327.
- Bengtsson, S., & Bonfils, I.S. (2013). Danish disability research across half a century. *Scandinavian Journal of Disability Research*, 15(sup1), 13-37.
- Bury, M. (1997). Disability and the myth of the independent researcher: a reply. In Barton, L., & Oliver, M., (eds), *'Disability studies: Past present and future'* (pp. 244-248). Leeds: The Disability Press.
- Bury, M. (1996). Defining and researching disability: Challenges and responses. In Barnes C., & Mercer, G., (eds), *'Exploring the divide'* (pp. 18-38). Leeds: The Disability Press.
- Danieli, A., & Woodhams, C. (2005). Emancipatory research methodology and disability: A critique. *International Journal of Social Research Methodology*, 8(4), 281-296.
- Devakumar, D., Brotherton, H., Halbert, J., Clarke, A., Prost, A., & Hall, J. (2013). Taking ethical photos Of children For medical and research purposes In low-resource settings: An exploratory qualitative study. *BMC Medical Ethics*, 14(27).
- Duckett, P.S., & Pratt, R. (2001). The researched opinions on research: Visually impaired people and visual impairment research. *Disability & Society*, 16(6), 815-835.
- Kidney, C.A., & McDonald, K.E. (2014). A toolkit for accessible and respectful engagement in research, *Disability & Society*, 29(7), 1013-1030.
- Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society*, 15(1), 25-47.
- Kntayya, M. (2000). *Ketaksamaan sosial*. Kuala Lumpur: Utusan Publications & Distributors Sdn. Bhd.
- Kroll, T. (2008). *Focus on disability: Trends in research and application*. New York: Nova Science Publishers Inc.
- Llewellyn, G. (2014). *Report of audit of disability research in Australia*. Center for Disability Research and Policy.
- McKenzie, J., Mji, G., & Gcaza, S. (2014). With or without us? An audit of disability research in the southern African region. *African Journal of Disability*, 3(2).
- Mercer, G. (2004). From critique to practice: Emancipatory disability research. In Barnes, C., & Mercer, G. (eds), *'Implementing the social model of disability: Theory and research'* (pp. 118-137). Leeds: The Disability Press.
- Mji, G., Schneider, M., Vergunst, R., & Swartz, L. (2014). On the ethics Of being photographed in research in rural South Africa: Views of people with disabilities. *Disability & Society*, 29(5), 714-723.
- Morris, J. (1992). Personal and political: A feminist perspective on researching physical disability. *Disability, Handicap & Society*, 7(2), 157-166.
- Morris, R.J. (2006). *Disability Research and Policy: Current Perspectives*. New Jersey: Lawrence Erlbaum Associates Inc.
- Oliver, M. (2002). *Emancipatory research: A vehicle for social transformation or policy development*. Paper presented at the 1st Annual Disability Research Seminar, hosted by The National Disability Authority & The Center for Disability Studies, University College Dublin, held at Great Southern Hotel, 3 December 2002.
- Oliver, M. (1997). Emancipatory research: Realistic goal or impossible dream?. In Barnes C. & Mercer G. (eds), *Doing disability research* (pp. 15-31). Leeds, The Disability Press.
- Oliver, M. (1992). Changing the social relations of research production?. *Disability, Handicap & Society*, 7(2), 101-114.
- Priestley, M. (1997) Who's research?: A personal audit. In Barnes, C., & Mercer, G., (eds.), *'Doing disability research'* (pp. 88-107). Leeds, The Disability Press.
- Priestley, M., Waddington, L., & Bessozi, C. (2010). Towards an agenda for disability research in Europe: Learning from Disabled People Organisations. *Disability & Society*, 25(6), 731-745.
- Rioux, M.H. (1997). When myths masquerade as science: Disability research from an equality-rights perspective. In Barton, L., & Oliver, M., (eds.), *'Disability studies: Past, present and future'*. Leeds: The Disability Press.
- Salovvita, T. (2013). Lines of development in social research on disability in Finland between the years 1970-2010. *Scandinavian Journal of Disability Research*, 15(Sup1), 38-54.
- Shakespeare, T. (2015). *Disability research today: International perspectives*. London: Routledge.
- Shakespeare, T. (1997). Rules of engagement: Changing disability research. In Barton, L., & Oliver, M., (eds), *'Disability studies: Past present and future'* (pp. 248-253). Leeds: The Disability Press.
- Shakespeare, T. (1996). Rules of engagement: Doing disability research. *Disability & Society*, 11(1), 115-121.
- Soder, M. (2013). Swedish social disability research: A short version of a long story. *Scandinavian Journal of Disability Research*, 15(Sup1), 90-107.
- Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. (Online). Retrieved from <http://eprints.whiterose.ac.uk/archive/00000927/>
- Tossebro, J. (2013). Two decades of disability research in Norway – 1990-2010. *Scandinavian Journal of Disability*

Research, 15(Sup1), 71-89.

Wappett, M., & Arndt, K. (2013a). *Foundation of disability studies*. New York: Palgrave Macmillan.

Wappett, M., & Arndt, K. (2013b). *Emerging perspectives on disability studies*. New York: Palgrave Macmillan.

Widom, C.S., & Czaja, S.J. (2005). Reactions to research participation in vulnerable subgroups. *Accountability in Research, 12(2)*, 115-138.

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap & Society, 7(2)*, 125-138.