

THE ROLES OF ORGANIZATIONS FOR BLIND PERSONS IN RESEARCH-ORIENTED ACTIVITIES: A RESEARCH PROPOSAL

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ABSTRACT

The present paper conceptualizes the first author's preliminary foundation for his doctoral research which is to investigate the roles played by Malaysian organisations for blind persons in disability research production. Ensuing from the standpoint that local organizations for blind persons as the focal point of knowledge providers and experts in issues relating to blind and visually impaired persons, we position these entities in a broader socio-political dimension of disability research production in Malaysia. The proposed study utilizes ethnography as its methodological framework. The researched communities for this study comprise two local organizations for blind persons located in Klang Valley. Besides identifying the roles of Malaysian organizations for blind persons in research-related activities, the proposed study also aims to explore challenges encountered by these organizations in carrying out research-related activities and to interrogate the outcomes from such activities. The final objective is to propose mechanisms in facilitating research-related activities of Malaysian organizations for blind persons. Basing on critical realism as its core theoretical framework, the study considers the integration of the biopower philosophy, the relational methodology of research production, and the methodical model of disability research production. Potential contributions and limitations of the study are also discussed.

Keywords: Biopower, critical realism, disability research production, ethnography, organizations for blind persons

INTRODUCTION

In 2019, Elsevier and Ipsos MORI published a report entitled "Research futures: Drivers and scenarios for the next decade". Based on the data gathered through a series of expert interviews, surveys, and workshops, the report presents six possible themes; research funding, the culture of open science, research production, technological integration, future research information system, and the shift of higher learning practices (Elsevier & Ipsos MORI, 2019, pp. 6-7). As we read through the report, we continue to wonder about the position, outcomes, and relationships between the disabled Malaysian community and their representative organizations in this rapidly changing technological- and industrial-oriented research ecosystem.

The report, however, only focuses on the merge between industry/market-led agenda with the research production ecosystem in the higher learning sector. This may expose such a merge to be severed from and void of human-societal connections in knowledge production. Hence, it renders our view of the research ecosystem and its future to be somewhat limited and narrowed, overlooking more important stakes, which are the human and societal implications of research activities. Elements such as voices, interests, and participation of the general public and other social institutions must also be considered here. Though the research ecosystem requires funding to be sustained and money is mostly produced by business activities, it does not mean the industry/market has a greater value over human-societal aspects in knowledge production.

Traditionally, we view universities as the main machine and the sole player in knowledge production in our society. But, if we take a step back and reflect on current reality, three other entities engage with data collection. Those entities are government, private sector, and international organizations. Though each of these entities has different underlying goals, they collect and produce various forms of results that inform decisions or even create change. We argue that there is the fifth player in the current research environment which is non-governmental organizations.

As parts of civil society movements increasingly recognize the importance of data for policy advocacy (Kaare, Chowdhury, & Kazi, 2007; Nabalema, 2015) and advocacy impact evaluation (Naeve, Fischer-Mackey, Puri, Bhatia, & Yegbeme, 2017), we observe a surging number of research-related activities either initiated primarily by non-governmental organizations themselves or through collaborative efforts with higher learning institutions.

In the context of the merge between disability research production and disabled people's advocacy, there is a mountain of work and continuous debate (Fontes, Martins, & Hespanha, 2014; Morris, 1992; Nasir, Efendi, & Hussain, 2019; Nasir & Hussain, 2018, 2019; Shakespeare, 1996, 1997). These lead to a transformation of the position and relationships of disabled people to research production, from 'damaged objects' to "expert knowers" and "research co-producers" (Shakespeare, 2018; Stone & Priestley, 1996; Stubbs, 1999; Priestley, 1997). There is also a rise in inclusive research and participatory research involving

persons with impairment and/or chronic illness (Butler, Cresswell, Giatras, & Tuffrey-Wijne, 2012; Nind & Vinha, 2012a, 2012b; Sample, 1996).

It is interesting to study the position and relationships of Malaysian disabled people's organizations to disability research production; how do these organizations perceive disability research? To what extent do these organizations engage in local disability research production? How do these organizations shape the local disability research ecosystem, hence the institutionalization of disability studies in Malaysia? It is worth noting that an exploratory study in the Republic of the Philippines finds that disabled people's organizations play an active and important role in carrying out and affecting disability research discourse (Nasir, Efendi, & Hussain, 2019).

The present paper propounds the first author's doctoral research proposal that investigates the roles of two Malaysian organizations for blind persons in disability research production. The proposed study is guided by four objectives: (1) to identify the roles of Malaysian organizations for blind persons in research-related activities; (2) to explore challenges encountered by the Malaysian organizations for blind persons in carrying out research-related activities; (3) to interrogate the outcomes from research-related activities by Malaysian organizations for blind persons; and, (4) to propose mechanisms in facilitating research-related activities of Malaysian organizations for blind persons.

Three poignant factors push for the conduct of this study. First, as the first author and colleagues have demonstrated elsewhere (Nasir, Efendi, Lau, & Wong, 2020a, 2020b), Asian and the Pacific countries are facing data crisis concerning the situation of persons with impairment and/or chronic illness in the region. Therefore, we assert that local organizations for/of disabled people, in this case, organizations for blind persons in Malaysia, have the opportunity and duty to fill up the data gap. Second, agreeing to Gooding's (2014) assessment of the potential possessed by non-governmental organizations in research, we assert local organizations for/of disabled people share similar advantages as service providers to their member community.

The third reason is the value of knowledge and lived experience amongst the disabled community members as the 'researched community', 'users', and 'recipients' of the disability research activities and their impact. For clarity and consistency, the next heading explains the operational definition of the terms used in the present study. Afterwards, this paper provides a review of literature relating to the research topic. Following that, we present the theoretical, conceptual, and methodological frameworks. Finally, we conclude by highlighting some of the research significance and its limitations.

OPERATIONAL DEFINITION

"Blind people" or "blind persons" or "persons with visual impairment"

In the present study, these three terms (blind people, blind persons, and persons with visual impairment) are used interchangeably. These three terms are used to refer to the whole community of persons who are blind and/or have low vision. However, this group does not include those who have a long-sighted or short-sighted vision. This group only consists of persons who have the level of vision deemed as blindness or severe visual impairment based on one of these measurements/diagnoses listed on the official portal of the Department of Social Welfare:

1. Low vision in both eyes – vision is worse than 6/18 but equal to or better than 3/60 even when using vision aid or the field of vision is less than twenty degrees from fixation.
2. Blind in both eyes – vision is less than 3/60 or the field of vision is less than ten degrees from fixation for both eyes.
3. Blind in one eye – vision is less than 3/60 or the field of vision is less than ten degrees from fixation in one eye.
4. Other permanent visual impairments for example albinism.

They can be members of either one of the organizations selected as the researched communities or otherwise. The difference between the term 'blind people/persons' and 'persons with visual impairment' is related to the philosophy of language use. Blind people or blind persons is an identity-first language, whereas persons with visual impairment is a person-first language. To put it simply, identity-first language affirms any and all impairments, such as blindness as an important part of one's identity, while person-first language emphasizes that everyone is a human first and should not be identified by his or her medicalized definition of impairment. The first author understands and accepts both sentiments because of his ontological and epistemological standing with respect to the term's impairment and disability.

The first author strongly affirms that impairment does not cause disability, which is one of the basic underlying statements of the social model of disability, even in his theoretical framework of disability which he calls the neo-biopsychosocial model of disability (Nasir & Efendi, 2018). Everyone, including blind people, is human and as humans, we can seek, understand, develop, and claim our identities without disabling comparisons or connotations ascribed to any parts of our identities. When the first author uses the term 'blind people/person', he is not dismissing one's personhood and only focusing on blindness. At the same time, when he uses the term 'persons with visual impairment', it does not mean he is dismissing one's ownership of his/her blindness as part of one's identity.

“Disability”

Previously, the first author and his colleague wrote a paper (Nasir & Efendi, 2018) proposing a new model of disability. The model is called the neo-biopsychosocial model of disability. There are four basic tenets to the model:

1. Disability is a continuous process of having to face or not to face barriers and risks of barriers;
2. Barriers and risks of barriers exist due to negative relationships between the domain of self, the society, and the environment;
3. The driving force of disability is inaccurate episteme that constructs, reproduces, and reinforces those negative relationships; and,
4. The outcomes and effects of disability are translated into material and abstract inequalities among disabled people.

Inaccurate episteme comes not only in the form of negative perception that results in poor attitudes toward or stigmatization of one's impairment and/or chronic illness. Inaccurate episteme, in fact, can be transmitted to and affected other social, cultural, technological, environmental, economic, and political dimensions (Nasir & Efendi, 2019a, 2019b).

“Disabled people” or “disabled persons” or “persons with impairment and/or chronic illness”

The first author also uses these three terms (disabled people, disabled persons, and persons with impairment and/or chronic illness) interchangeably. Different from the argument of using the terms ‘blind people/persons’ and ‘persons with visual impairment’, the justification necessitates a critical understanding of the concept ‘disability’ as explained above. The term ‘disabled people/persons’ is used to showcase a group of individuals who become disabled because of disabling intersections between the domain of self, society, and the environment due to inaccurate episteme.

The use of the term ‘disabled persons/people’ is not to focus on their impairment or deny their personhood, but to highlight the symptoms and outcomes of disablement in society on these groups of people. On the other hand, the use of the term ‘persons with impairment and/or chronic illness’ not to dismiss the barriers they encountered or to focus on their biological conditions, but because all of us, including persons living with some form of impairment and/or chronic illness, are humans. However, the present study does not use the term “persons/people with disabilities”, unless the term is used as part of the official title of a policy, international convention, or legislation, because such a term makes the disability concept, which is disabling intersections between the domain of self, the society, and the environment as a good, neutral, and natural occurrence attached to one's being a human.

“Organizations for blind persons”

In general, there are two major categories of an organization representing disabled people; organization of disabled people and organization for disabled people. The difference between ‘for’ and ‘of’ lies with the nature of such organizations. Organizations of disabled people, or mostly referred to as disabled people's organizations, are established and managed by disabled people themselves. Its membership is primarily comprised of disabled individuals even though they also recruit non-disabled people as volunteers or associate members. These organizations may also employ non-disabled employees, but disabled members hold the highest power and authority in such organizations. Most organizations of disabled people are designed as self-help organizations for the benefit of their members. An example of the organization of disabled people is the Society of the Blind in Malaysia (SBM).

Organizations for disabled people, on the other hand, are established and usually managed by non-disabled individuals such as parents, professionals, activists, and volunteers. The membership and administration are sometimes open to both disabled and non-disabled people. These organizations may also employ disabled individuals alongside their non-disabled counterparts. The aim is still similar to the organizations of disabled people, which is to better the living situation of their target community. Other organizations may be designed as support groups or voluntary community work. An example of an organization for disabled people is the St. Nicholas Home for the Blind.

The same principle then also applied to organizations representing blind persons. Organizations of blind people refer to organizations established and managed by blind persons themselves, whereas organizations for blind persons are opposite to that. Despite this categorization, both types of organizations do work together on an issue from time to time. Nonetheless, the differences are visible. Though there is a possibility for a collaborative type of organization, where both disabled and non-disabled people have mutual share and power in that particular organization, there is yet to see such a movement in Malaysia, at least in the sense of genuine mutual ownership.

“Disability research”

Disability research refers to the conduct of systematic and scientific procedures of inquiring about an issue affecting or involving persons with impairment and/or chronic illness or a group of people who may have a connection and/or interaction with persons with impairment and/or chronic illness. Disability research, like any other research, collects data either from primary and/or secondary sources. Notwithstanding the basic components of doing research (for example data collection, data analysis, and research reporting), we must not limit our understanding of research conduct only within the realm of higher learning

institutions. As argued before, other entities such as government and non-governmental organizations are also engaged in research activities.

LITERATURE REVIEW

Data and information are valuable resources in today's world as the stronger emphasis is being put on, or at least the optic of its importance, on various sectors these days. Be it in the public sector or the business sector. Governments and international bodies push for agendas relating to data mining and data application to produce informed policies, or otherwise known as evidence-based or data-driven policies. Data is vital to fulfilling a certain form of interest, such as in marketing for profit-making or assessing voters' support in an election. The importance of data is further strengthened with the rising of the fourth industrial revolution, where big data analytics and advanced technological innovations become the spearheading factor of human life – at least from the industrial economic point of view.

Data is commonly gathered by a systematic process that most people recognize as research. Research has been around human life since the earliest civilizations. Over time, research becomes more sophisticated both theoretically and methodologically with the emergence of diverse scientific fields. Today, research becomes an inherent part of any field and study program, from diploma to doctoral studies. However, van den Akker and Spaapen (2017) argue that knowledge production today is more fluid in comparison to the conventional research process thinking and requires and often relies on interaction with other social domains outside academia.

Without reliable and comparable data on the situation of persons with impairment and/or chronic illness, governments are unable to properly plan and implement appropriate policies and programs effectively. This is one of the major issues binding Asian and the Pacific countries (Economic and Social Commission for Asia and the Pacific, 2012, 2016, 2018). This is where, we believe, disabled people's organizations can contribute to collating data and producing research besides data collection activities by government agencies and academicians. Having said that, disabled people's organizations may not acknowledge the importance of disability research and under-prioritize this function altogether (Nasir et al., 2020a).

The roles and functions of any disabled people's organizations primarily to serve its members – the disabled people who they represent. A recent literature review on the function and impact of disabled people's organizations in low and middle-income countries suggests these organizations can bring positive change in terms of economic and social empowerment (Young, Reeve, & Grills, 2016). The aspiration and message of change have long been integrated into disabled people's movements around the world. At the same time, the idea of the emancipation of disabled persons from their life struggles begins with the promotion of the emancipatory paradigm in researching disability (Oliver, 1990, 1992, 1997, 2002).

Increasingly, we can see efforts from the regional and international organizations concerning persons with impairment and/or chronic illness collecting data. These efforts are even more concentrated during the COVID-19 pandemic outbreak. Such organizations include the World Blind Union, International Disability Alliance, European Network of Independent Living, and Pacific Disability Forum. Locally, we observe a few data-related initiatives among organizations and individuals to ensure appropriate support is provided to the disabled community facing the social and economic impact of the pandemic.

The investigation of the roles of disabled people's organizations in disability research production calls for critical inquiry into aspects such as local wisdom within the disabled community about disablement, disabled people's relationships to knowledge production, localization of foreign ideas, and biopower dynamics (Nasir et al., 2020a, p. 7). Furthermore, there are issues involving monetary resources/investment (Nasir & Hussain, 2018, 2019; Zarb, 1992) as well as organizational leadership that promotes and facilitates knowledge production.

In a broader scope, the disabled community and their representative organizations are part of society that interact with different social, economic, and political institutions (Nasir & Efendi, 2018, p. 30). Therefore, we must also consider the influence of disabled people's organizations (including the disabled people's movement) on other institutions such as policymaking, social and cultural narratives of disability, and knowledge production. Equally important is the interactions within the disabled community across impairment groups and their effects on the overall disabled people's politics, advocacy, and wisdom.

THEORETICAL PROPOSAL

The study adopts critical realism as its theoretical and methodological philosophy. In developing the theoretical framework, critical realism provides two key underlying assumptions: (1) certain properties, powers, and mechanisms produce a social phenomenon; and, (2) emphasis on the structural analysis (Danermark, Ekstrum, Jakobsen, & Karlsson, 2002). Thus, there is a need to break down each of the following aspects in the context of this study: (a) properties of disability research; (b) power relations in disability research; (c) mechanisms of disability research; and, (d) structures in disability research.

Past work in disability studies since the early 1990s have discussed extensively the properties of disability research (Morris, 1992; Oliver, 1992, 1997; Shakespeare, 1996; Stone & Priestley, 1996; Zarb, 1992). To scrutinize the conduct of disability research, there are two important levels of inquiry one must undertake; the first level is the inquiry of disability as a phenomenon and the second level is the inquiry of the research activity. The conduct of disability research must be discussed in two interconnected domains; the philosophy (the ontological, epistemological, and moral standpoint) as well as the praxis (the process of actions) – hence the overlap between internal and external structures of research (Nasir & Hussain, 2018, p. 43).

We extend the properties of disability research by proposing eight principles of the methodical model of disability research production (Ibid, pp. 46-47). Those principles are:

1. Emancipatory-inclusionary intention;
2. Immersion into the issue;
3. Active and respectful engagement;
4. Reciprocal and gainful relationship;
5. Accessible, flexible, and empowering methodologies;
6. Ethical, responsible, and reflexive implementation;
7. Impactful and responsive outcomes; and,
8. Continuous communication.

However, admittedly we propose the above-mentioned principles from the viewpoint of individuals conducting research and do not consider the interaction of two or more organizations on a broader scale. Though we do think some of the principles laid out above can be adapted into broader inter-organizational relationships, yet we realize its shortcomings, particularly with respect to enabling/disabling mechanisms and socio-political/socio-cultural structures of knowledge production. Although the model above discusses the relationships between different stakeholders in a research project, we admit the discussion is superficial in terms of power relations and power utilization. Therefore, the work of Michelle Foucault on biopower is very relevant and crucial in this research topic.

On biopower relations in disability research philosophy and praxis, we expand the work of Shelley Tremain (2005, 2017), a disabled philosopher of disability who has worked extensively on the issue of biopower or biopolitics philosophy of disability. Tremain (2005, p. 11) asserts that disability is a product of various apparatus to distinguish, segregate, and contrast a group of persons to another group of persons which they are conditioned to accept and conduct in certain ways thus naturalizing and institutionalizing the effects of their regulated conditions. Besides the obvious form of segregation such as asylums and nursing homes, she postulates administrative actions such as the categorization of impairment groups disguises as statistical measures for any reason also impose and dictate one's as well as others' actions toward those categorizations of impairment types.

In her second book, Tremain (2017) expands the conceptualization of disability as an apparatus of power by introducing the Foucauldian analysis of discourse which is historically and culturally situated. She contends that Foucauldian analysis of discourse can explain: (1) the reinforcement and expansion of the apparatus of disability through the philosophical discourses; (2) the dismissal of serious criticisms regarding the apparatus of disability within the professional intellectual sphere; and, (3) resistance towards the apparatus of disability. The same line of inquiry can also be used to examine disability research activities as an intellectual/advocacy tool.

The history of disability studies scholarship, especially in the United Kingdom, shows that disabled scholars and activists had resisted and criticized the theoretical and methodological conduct of disability research. We know from this radical movement, two key ideas emerged and revolutionized the discussion surrounding disability, which is the social model of disability and the emancipatory disability research paradigm. Despite this, one constant major critique of disability research is its failure to produce meaningful changes in disabled people's life. From Kitchin's work (2000) to Duckett and Pratt's (2001), to the first author's and colleagues' recent work on the topic (Nasir, Efendi, & Hussain, 2019; Nasir et al., 2020a, 2020b; Nasir & Hussain, 2019) come to the same conclusion.

Though in Malaysia there is no study program specializing in disability studies, we observe the increase in interest in disability research among local researchers and students. As issues relating to disability and disabled people are becoming more morally and/or intellectually enticing, besides other development such as the evolution of disability studies as a career choice and the push by international bodies concerning disability prevalence data, perhaps the question of biopower/biopolitics of disability research are also increasingly valid and desperately needed.

The question of biopower/biopolitics of disability research production exists at least in two interconnected apparatus; the researchers themselves (such as privileged positions in society, credentials, and enabling/disabling identity presentations) and the research process itself (i.e. data collection, analysis, and publications). The combination of these apparatus and other elements in disability research production (properties, mechanisms, and structures) resulting in various possibilities of relationships and effects, either causing frictions or nurturing a supportive ecosystem.

As to mechanisms of disability research, there are three obvious aspects; the existence of capable human resources, funding, and leadership. Scholars of disability studies in the 1990s had discussed issues surrounding funding for disability research projects (Oliver, 1997; Zarb, 1992; see also Nasir & Hussain, 2018, 2019). As this study situates in the non-governmental organization ecosystem, the position and relationships are different. Academicians, even amongst disabled academicians, may have greater access to research funding since they occupy legitimate intellectual positions as academicians at their respective institutions

which automatically present their ‘credibility’ to conduct research. Employees of non-governmental organizations, and to a similar extent, independent researchers do not have the same advantages as academicians do in this context.

Non-governmental organizations rely on three sources of income: (1) membership fee; (2) government funding; and, (3) donation, either from the public, private sector, or other funding bodies. First, non-governmental organizations are usually associated with community work or care work (the charity) instead of ‘professional intellectual work’ even though these organizations provide specialized professional services to their clients or members – which indeed is very true for organizations for/of disabled people. Such presumptions may not yield sufficient ‘confidence’ among funders. Second, access to and opportunity for funding closely relates to networking resources possessed by these organizations or certain individuals within these organizations. This again involves the question of positionality and power that enables someone to achieve or do something.

The second mechanism of disability research is leadership. Though there is a study by Organization for Economic Cooperation and Development discusses the roles of leadership in research and innovation management (Olsson & Meek, n.d.), there is a need to research the same element in non-governmental organizations’ context. The issue of leadership points to two very relevant aspects: (i) the nurturing of research culture and climate in these organizations; and, (ii) the question of structure and social relationships within these organizations. Like in many government agencies and private companies, non-governmental organizations still practise a conventional arrangement of organizational structure – more vertical than horizontal. This encourages the scrutiny of the degree of control among employees charged with research-related activities.

Regarding research culture and climate in an organization, it does not necessarily mean or dictate organization must have a unit or department charged specifically on research – though a clear structure and function may have more visible effects. The trace of research culture and climate in an organization can be very subtle such as the emphasis on input gathering before program or service development, concrete reporting and documentation, and the conduct of service or program assessment. These are some of the useful grounds for evidence-based advocacy for non-governmental organizations. It begins with the critical consciousness of disability and the recognition of the importance of data/research among people operating the organization.

The third mechanism, finally, is the existence of human resources. In higher learning institutions, human resources are endless. Besides academicians, there is a continuous stream of students, both at undergraduate and postgraduate levels. For non-governmental organizations, even if these organizations emphasize the importance of research activities, such organizations may have limitations in capital to hire capable human resources. Currently, there are two possible strategies. The first strategy is to collaborate with higher learning institutions to conduct research. The second is to hire research consultants to research on behalf of the organization. The latter gives somewhat more control to the organization compare to the first strategy. Nevertheless, both situations require careful navigation of relationships between different actors involved.

The last major component, which is the structures of disability research, links back to the question of positionality, power, and relationships. Here, the structures of disability research are not about the procedural actions of research conduct, instead refers to the interactions between different individuals and groups throughout the research process. As briefly discussed above, the organizational structure may affect the freedom or flexibility of the research work. Some of the relevant questions are: (a) does a particular organizational structure produce bureaucratized ecosystem for research, hence disrupting it? (b) what and how a bureaucratized research ecosystem affects the organization’s working relationships with other research partners?

This is where the principles of the relational methodology of research production proposed by Tregaskis and Goodley (2005) are relevant. They submit four efficacious propositions summarized as follows:

1. Recognizing and challenging internalized oppression due to the disabling construction of impairment effects within the working relationships between disabled and non-disabled researchers.
2. Valuing and drawing from personal ontologies and experiences regarding disability to describe and analyze disablement in society.
3. Resisting the over-emphasis on individualist conduct of research and embracing interdependent relationships between research team members via supportive and cooperative working conditions.
4. Producing enriched analysis of the research topic through mutual trust and shared commonalities to experiences of disablement, not only between the disabled and non-disabled researchers, but also the research participants and other involved parties.

Ultimately, the inquiry of this topic exposes the social, cultural, institutional, and political aspects of research activity where most of the time such elements are silently influencing our conscious actions. The next step is to proffer a conceptual framework that seeks to redefine and reconfigure the connections of the four aforementioned subtopics (properties, power relations, mechanisms, and structures).

CONCEPTUAL PROPOSAL

We must first emphasize here that the present conceptual proposal is still in its very early stage of conceptualization. Yet, we seek to posit a framework, not only relevant in the contexts of the researched communities for this study (i.e. organizations for blind persons) but foreseeing possible circumstances in knowledge/research co-production between organizations for blind persons and research institutions as well as independent researchers. Building on the theoretical framework proposed in the previous section, we submit a conceptual framework comprised of the following concepts:

1. Episteme.

There must be a clear and firm shared critical consciousness of disability as a phenomenon and disability research as intellectual, institutional, social, and political apparatus. All participating parties must navigate their personal, intellectual, professional, and political interests in doing a particular disability research project. Generally, all participating parties in a disability research project must have consensual agreements on the following aspects before the project can be carried out:

- (a) The ontological and epistemological standpoint on disability.
- (b) The end goal and outcomes from the disability research project.
- (c) Flexibility and reflexivity of the research process.
- (d) The sharing of resources and distribution of workload.

For any disagreements, they must be reconciliation. As such, all participating parties must work together to establish a space and opportunities to meaningfully address the disagreements. Though these engagements can be contentious, all participating parties must continue to be respectful of each other. There are many potentials for disagreements, from the major issues (the four aforementioned items) to the minor but still damaging issues such as the use of specific terminologies. No disagreement, how small it may be, should be dismissed. The episteme of a disability research project directly affects the other three concepts discussed below.

2. Support.

All participating parties must identify and share resources necessary for the implementation of the disability research project, both personal and institutional resources. These resources include personal knowledge and experiences, funding, access to research participants, research skills, access to technologies, and other research-enabling factors. For resources they do not have, participating parties must work together to identify and formulate strategies to acquire such resources, including engaging external parties who can facilitate the application/provision process.

3. Care.

Participating parties must recognize, embody, and practise interdependence in conducting and completing the disability research project. As such, participating parties must move away from the individualistic conduct of research. Certain positions in an organization, affiliation, or possessing certain skills do not mean other positions, affiliation and skillset are inferior. Instead, participating parties complement each other, thus creating a network of support, cooperation, and care among team members. The same network of support, cooperation, and care must be built with research participants. This is also imperative in materializing the effects (or outcomes) of the research project.

4. Effect.

As insisted by previous writings and research, a disability research project must not be limited to become a theoretical endeavour or propaganda. Disability research must provide actionable solutions to bring change to disabled people's life. This is where the three earlier concepts discussed above (episteme, support, and care) must merge. This means participating parties must break away from transactional and detach-objective relationships that design the conventional practice of knowledge production. As allies, participating parties are attached to the cause and the researched community. Accepting and embracing this new reality of allyship for and from disability research production further strengthen the merge of intellectual and political discourses for disability emancipation.

METHODOLOGICAL PROPOSAL

The proposed study adopts an ethnographic research methodology. This is because this research aims to understand subjective elements such as history, experience, attitude, perception, and aspirations. Ethnography today has evolved to be a very useful tool in developing and implementing policy (Mosse, 2005). Ethnography is widely used in different fields such as education, science and technology, communication, children studies, and deviance. Ethnography is also being advocated as a useful tool in disability studies (Davis, 2000). There is a range of ethnographic work on issues affecting persons with impairment and/or chronic illness (see for example de Wolfe, 2013; Efendi, 2019; Neary, 1999).

According to Lebar (2012, p. 95), an ethnographic study is an explanation or a process to construct symbolic meanings and ways of interaction among its research participants. Another scholar, Awang (1996, p. 2) provides three main definitions of ethnography, which are: (a) an empirical depiction of culture and social organisation within a society; (b) a set of qualitative research procedures which is carried out intensively in order to research a society; and, (c) an academic subject which investigates cross-cultural comparison. Thus, O'Reilly (2012, p. 3) summarizes the crucial elements of ethnographic research as:

“... Ethnography is a practice that evolves in design as the study progress; involves direct and sustained contact with human beings, in the context of their daily lives, over a prolonged period of time; draws on a family of methods, usually including participant observation and conversation; respects the complexity of the social world; and therefore tells rich sensitive and credible stories. Ethnography should be informed by a theory of practice that: understands social life as the outcome of the interaction of structure and agency through the practice of everyday life; examines social life as it unfolds, including looking at how people feel, in the context of their communities, and with some analysis of wider structures, over time; also examines, reflexively, one's own role in the construction of social life as ethnography unfolds; and determines the methods on which to draw and how to apply them as part of the ongoing, reflexive practice of ethnography.”

However, for this research, we choose to conduct an ethnographic study in two local organizations for blind persons in Malaysia – hereinafter we will refer to as Organization Q and Organization R. Both Organization Q and Organization R are located in Klang Valley, Malaysia. For the record, there is a number of organizations catering to blind persons established and located in Klang Valley besides associations representing other impairment groups. There is a couple of reasons we choose these organizations. First, these organizations have a unit on research. This signals that these organizations have a conscious effort to conduct research, or at least promote and facilitate such activities.

Secondly, the first author has been fortunate to have worked alongside the people at these organizations in several programs and initiatives. The first author has been involved in their empowerment programs, as well as a few of the organizations' research projects. This enables us to identify and build relationships with the key informants in these organizations, which is very helpful in strengthening sample accessibility (Nasir & Hussain, 2018).

This proposed study utilizes primary data. Primary data refers to raw unsystematic information that can be extracted from texts, visual or verbal. We collect primary data exclusively from the research informants. The pool of our research informants comprises the workers and leaders affiliated with these two organizations. We select research informants among the council members and workers at these organizations, including the Executive Director and the Manager of the research unit. Those informants under the category of workers can be either full-time or part-time employees serving these organizations. Due to the fact the present study also encompasses historical accounts of these organizations' research activities, there is a possibility to collect data from ex-council members and ex-employees of these organizations. The number of informants for this study is expected to be between three to seven informants for each organization. We combine the use of purposeful sampling and snowball technique in selecting research informants.

The first author plans to conduct at least two rounds of interviews with each research informant. The interviews will be guided by a semi-structured interview schedule. We develop two sets of interview schedules, one specifically for informants among workers and ex-workers, and another set is specifically for informants among leaders and ex-leaders. All interview sessions will be recorded for the transcription and interpretation process. A combination of thematic analysis and qualitative comparative analysis will be used to analyze the data.

CONCLUSION

We assert the proposed study signifies four key areas. First, the proposed study gives central attention to the local wisdom amongst the disabled community in Malaysia with regards to disablement and inclusion. In other words, the proposed study recognizes and seeks to promote the recognition of the local wisdom amongst this marginalized group. Subsequently, the proposed study can nurture an emancipatory epistemic climate among policymakers so they can develop effective policies to safeguard the rights of citizens with impairment and/or chronic illness.

Second, the proposed study proposes the potential roles and contribution of local organizations for and of blind persons in disability-related knowledge and research production processes, hence the democratization of knowledge production processes in this country. The third key area is related to the second key area above-mentioned, however, it is more contextualized in the realm of higher learning institutions. The proposed study encourages actors in higher education, which can be extended to independent and government-linked research centres, to do at least three things:

1. Recognize the local wisdom about disablement and inclusion, focusing on the lived experience and expertise amongst the disabled community;
2. Practice plural epistemologies and methodologies which aim toward full and meaningful emancipation of persons with impairment and/or chronic illness; and,
3. Consult and collaborate with local blind people's organizations and other associations representing various impairment groups in Malaysia to carry out research projects concerning disability issues.

Finally, the proposed study pursues the advocacy goal for the institutionalization of disability studies in Malaysia (Nasir, Efendi & Hussain, 2019; Nasir, et. al. 2020a, 2020b; Nasir & Hussain, 2018, 2019). We observe there is a continuing increase in the quantity of disability-related research conducted, but we do not want the surge to end as meritocracy politics. Notwithstanding the three salient points above, there is a strong need and justification to mainstream disability studies as one of the recognized scientific fields in Malaysia. We hope the proposed study can serve as a needle that weaves the academic and political interests, producing the canvas of inclusionary framework for persons with impairment and/or chronic illness in this country.

Yet, we must address the limitations of the proposed study. The proposed study only investigates the research topic from the perspective of individuals affiliated and formerly affiliated with the two organizations identified as the researched community. The proposed study does not collect data from other relevant stakeholders such as government officials, academicians, and activists or organizations of different impairment groups. This results in highly subjective and contextualized viewpoints. Even though the first author will inquire about their experiences and relationships with external stakeholders such as the government, academicians, funding bodies, and other organizations of/for disabled people, these are from the research participants' perspective.

The present study primarily concerns with the internal situation of the two organizations selected as researched communities and to some extent outside factors that may majorly influence the internal situation. Notwithstanding many of the external social, cultural, political, and economic factors, certainly the present study can never cover such broad intersecting issues in a single research project, but at the same time, it will not be encapsulated with superficial elements such as challenges and successes without considering deeper interpersonal and inter-organizational connections of the matter.

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