

## THE ATTITUDES OF VISUALLY IMPAIRED YOUTHS IN THE ASIA-PACIFIC COUNTRIES TOWARD DISABILITY RESEARCH

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

Alfa Nur Aini Erman Efendi  
Independent Researcher  
E-mail: alfa.e.efendi@gmail.com

Christina Anne Lau Mei Kheng  
The representative of Japan Braille Library in Malaysia  
E-mail: christinalmk@gmail.com

Wong Yoon Loong  
National Council for the Blind, Malaysia  
Brickfields, 50470 Kuala Lumpur, Malaysia  
E-mail: wongyl@ncbm.org.my

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### ABSTRACT

*There is an increasing concern about the impact of research on society. One possible way to assess research impact is by studying societal attitudes toward research activities. This paper presents a part of findings from an online survey that aims to investigate the perspective of youths with visual impairment on disability research discourse in the Asia-Pacific region. 49 research participants from 17 Asian and the Pacific countries take part in the survey. We interpret the findings based on the average scores of each country. Our findings show that all countries, except for Kyrgyzstan in a couple of areas, have a positive attitude towards and view disability research as a critical tool for policy formulation, advocacy, service improvement, and disabled people empowerment. In addition, research participants from Brunei and Kyrgyzstan do not feel that disability research can bring positive change to disabled people's lives. In terms of negative exploitation by researchers, research participants from Indonesia, Laos, Mongolia, and Samoa do feel that researchers have a high tendency to exploit disabled people. We also find that our research participants respond positively to the idea of collaboration for research endeavors with other stakeholders in their countries. As argued by several disability studies scholars before us, we too call for the adoption of a critical realist paradigm to study disability issues.*

Key words: Asia-Pacific region, critical realism, disability research, research impact, youth with visual impairment.

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### INTRODUCTION

It is indisputable fact that the social model of disability pioneered by earliest disability scholars in the United Kingdom, as many have referred the model as the British social model of disability, brings a revolutionary insight in discussing disability and advocating for social and structural changes. Be that as it may, scholars from the global South argue that the British social model of disability has its limitations in the context of disabled people's situation in other countries, thus proposing alternative models such as the Nordic relational model of disability, the minority group model of disability, and the post-colonial approach to disability (Mallett & Runswick-Cole 2014).

The seemingly dominant global value arises from the British social model of disability, which most of the time due to its oversimplification, as well as the concerns regarding the risks of the hegemony of Western values packaged in a form of international convention, poses challenges to geopolitically and culturally diverse nations. These challenges can be seen in the areas of development (Grech 2016), global health (Swartz & Bantjes 2016), and statistics (Eide & Loeb 2016). It is not enough to simply criticize the global/local frictions without offering meaningful alternatives. Local scholars and activists must then draw from the local wisdom and indigenous knowledge to explain, interrogate, and provide strategies to remove disabilities at different levels in society.

Therefore, we must understand disabled persons' perceptions of the activities of disability research, especially in their countries. By understanding their attitudes toward disability research activities, we may potentially delineate the relationships and positions of disabled persons in disability-related knowledge production as well as their relationships with other vital actors (i.e. the insider and outsider scholars, activists, and disabled people's organizations). This article explores this very topic, collecting data from visually impaired youths in Asian and Pacific countries. The following section discusses past literature and we continue to describe the research methodology. Afterward, we present the analysis of the findings collected from our research participants. In the final section, we dissertate about possible ways to conduct critical realist research.

## LITERATURE REVIEW

A literature survey on studies concern with the societal impact of scientific studies finds there is still no comprehensive societal impact assessment framework due to its complexity. It is suggested the usage of case studies and qualitative assessment by both scientists in the field and other stakeholders can map the societal impact of research activities (Bornmann 2013). In their report, van den Akker & Spaapen (2017) assert that universities and scholars must practice collaboration with other stakeholders which transform the knowledge production processes to be more progressive, open, and inclusive, resulting in an interaction between the scientific institution and other social domains.

One proposal for evaluating the social and economic impact of academic research is to use the Research Excellence Framework (REF) which constitutes four major themes; allocation, advocacy, accountability, and analysis (Digital Science 2016, p. 2). The analysis of impact case studies also suggests diverse, interrelated, and global topics besides several critical hindrances such as high cost, high labor, exclude self-critical writings and no standardized unit of measure of impact (Ibid, pp. 2-3). This ultimately shows the conduct of societal impact appraisal of the academic research, either for global, national or institutional scale requires a vast network of resources and significant time investment.

However, Hayes (2019) argues the implementation of the Research Excellence Framework jeopardizes academic freedom as it only encourages mediocrity in knowledge production among scientists. The emphasis on the societal impact of research may hinder some scholars to engage in research topics which may not be deemed important or beneficial from the lens of societal impact. The same dilemma and pressure are more apparent among those identified as 'insider researchers' and even more so if their career survival hinges on immediate and commodified impact projects without appropriate ecosystem to meet such performance indicators.

Subsequently, this calls for deconstruction and reconfiguration of our understanding of the concept 'impact' itself. A societal impact or most may refer to as 'social change' from research, is a continuous process that involves various factors and strategies such as networking (Miles, Fefoame, Mulligan & Haque 2012) and identity (Gilchrist, Wetherell & Bowles 2010). Data is just one facet of epistemic action. Unfortunately, the challenges are there is a lack of reliable and comparable data on disabled persons across social, economic, and political dimensions (Economic and Social Commission for Asia and the Pacific 2007, 2012a, 2012b, 2016, 2018, 2019).

The reliability concept raises a few questions: Who defines the term? What are the epistemological foundations and ethical conduct of reliable research on disability issues? Does it dismiss self-critical writings and methodologies? As for comparability, different countries in the region may have their own set of priorities of issues or topics besides other factors such as the acknowledgment of the significance of disability research and its prioritization (Nasir, Efendi, Lau & Wong 2020).

The developing and poor countries may not have a sufficient number of well-trained scholars to do disability research or to supervise students conducting disability research, not counting other elements such as allocation (Nasir & Hussain 2018, 2019; Zarb 1992) and research interest among local scholars and students (Nasir, Efendi & Hussain 2019; Nasir, et. al. 2020). Policymakers and researchers in some countries may also find it difficult to match and balance between national, regional, and international priorities. Malaysia, for example, has its national action plan for disabled people and at the same time also abide by the Incheon Strategy and the ASEAN Enabling Masterplan 2025. Although these three instruments are interrelated and complement each other, the extensive and broad indicators may make the situation more confusing and complicated.

We believe societal attitudes toward research activities can potentially be a part of the matrix as well as a strategy to evaluate research impact to the society concerned (Duckett & Pratt 2001; Kitchin 2000; Nasir, Efendi & Hussain 2019; Nasir, Efendi, Lau & Wong 2020; Nasir & Hussain 2019). In the context of the disabled community, their opinion towards the research about them is imperative. Such reflection and assessment can help to inform future research and even policymaking processes to better represent their situations, interests, and experiences. Yet, past literature shows that the relationships between the disabled community and disability research production are complicated. Disability research-related activities are both celebrated and criticized for good reasons.

## METHODOLOGY

The explanation of the research methodology for this study has been made elsewhere (Nasir, Efendi, Lau & Wong 2020) since the present article draws from the same research endeavor. We choose to use quantitative research design to examine the general attitudes among our young research participants about the benefits and conduct of disability research in their home countries. However, as we emphasized in the other paper, the online survey can only uncover superficial facts about the research topic and must not be generalized to describe the situation in these countries. We design the present study to be exploratory quantitative research. Nonetheless, we strongly believe this study should not be repudiated because of its lack of generality.

Our research sample consists of youths with visual impairment living in Asian and Pacific countries. 49 research participants fill-up the online survey. They come from 17 countries in Asian and the Pacific region as shown in Table 1 below.

Table 1: Number of respondents according to country

Country	Number of respondents
Bangladesh	2
Bhutan	11
Brunei	1
Fiji	1
Indonesia	3
Kyrgyzstan	1
Laos	1
Malaysia	4
Mongolia	1
Myanmar	3
Nepal	1
Philippines	11
Samoa	2
Sri Lanka	2
Tajikistan	1
Tonga	1
Vietnam	3
Total	49

The highest number of respondents is from Bhutan and the Philippines, which is 11 respectively. Furthermore, countries such as Brunei, Fiji, Kyrgyzstan, Laos, Mongolia, Nepal, Tajikistan, and Tonga only have one respondent. The unequal number of respondents may cause by the digital gap in a few countries and the language barrier as hypothesized (Nasir, Efendi, Lau & Wong 2020). We also need to mind ourselves of the four factors of research participation among disabled persons which are research topic, research impact, time and location suitability, and token giving (Nasir & Hussain 2019).

Of these respondents, 18 of them (36.7%) are female and 31 respondents (63.3%) are male. 19 of them (38.8%) self-reported as having low vision and 30 of them (61.2%) are blind. Our respondents' age range is between 18 to 40 years old. 22 respondents (44.9%) report that they never take part as a research participant in any disability-related research and 27 of them (55.1%) have. Only 12 respondents (24.5%) have the experience of conducting disability-related research, whereas 37 respondents (75.5%) have not. With regards to affiliation to local disabled people's association, 10 respondents are not a member of any organization, while 26 participants hold a position in local disabled people's organizations at the time this survey was carried out.

We access the sample target through the database of ex-trainees of Teruko Ikeda ICT Training which is an annual ICT course funded and held by the Japan Braille Library for visually impaired youths from the Asian and the Pacific countries. Besides cluster sampling, we also use a snowball technique by encouraging the ex-trainees to share the survey with their peers. We initiate the data collection process by disseminating the online questionnaire through email. The questionnaire is designed using the Google Form application. The questionnaire comprises of two parts. Part A collects basic demographic background, whereas Part B collects respondents' perceptions of disability research production in their country. The questionnaire uses the English language since we want to gather data from international respondents. The data collection process lasts for about five weeks, starting in January of 2018 and ends in the first week of February of 2018.

During the analysis phase, we calculate the average score of each country. We assign a value to a specific range of average score: very negative (the average point of 1.99 and below); moderately negative (the average point between 2 to 2.99); least negative (the average point between 3 to 3.99); least positive (the average point between 4 to 4.99); moderately positive (the average point between 5 to 5.99); and, very positive (the average point between 6 to 7).

## DISCUSSION

As mentioned at the beginning of this paper, we want to investigate our respondents' attitudes toward disability research. Firstly, we are curious to analyze our respondents' belief on the impact of disability research on advocacy, policy development, service improvement, and disabled people's empowerment. From the data presented in Table 2 below, all countries score positively except for Kyrgyzstan which scores the least negative average point with regards to advocacy and service improvement. This shows that our respondents, except for Kyrgyzstan, have a positive attitude towards and view disability research as a critical tool to emancipate their lives condition. We find it quite fascinating and curious to understand the reasoning behind the negative scores by Kyrgyzstan towards the effects of disability research on advocacy and service improvement.

Table 2: Belief on the impact of disability research

Country	Average point			
	Advocacy	Disability Policy Formulation	Service Improvement	Disabled People's Empowerment
Bangladesh	6 (very positive)	6 (very positive)	7 (very positive)	5 (moderately positive)
Bhutan	6.5 (very positive)	6.7 (very positive)	6.1 (very positive)	6.5 (very positive)
Brunei	6 (very positive)	7 (very positive)	7 (very positive)	7 (very positive)
Fiji	7 (very positive)	7 (very positive)	7 (very positive)	7 (very positive)
Indonesia	5.3 (moderately positive)	6 (very positive)	5.7 (moderately positive)	5 (moderately positive)
Kyrgyzstan	3 (least negative)	4 (least positive)	3 (least negative)	4 (least positive)
Laos	6 (very positive)	7 (very positive)	6 (very positive)	6 (very positive)
Malaysia	5.3 (moderately positive)	5.3 (moderately positive)	5.3 (moderately positive)	5 (moderately positive)
Mongolia	6 (very positive)	7 (very positive)	5 (moderately positive)	4 (least positive)
Myanmar	6 (very positive)	6.7 (very positive)	6.3 (very positive)	6 (very positive)
Nepal	7 (very positive)	7 (very positive)	7 (very positive)	5 (moderately positive)
Philippines	6.3 (very positive)	6.4 (very positive)	6.3 (very positive)	5.9 (moderately positive)
Samoa	7 (very positive)	7 (very positive)	7 (very positive)	7 (very positive)
Sri Lanka	5 (moderately positive)	6 (very positive)	7 (very positive)	4 (least positive)
Tajikistan	5 (moderately positive)	5 (moderately positive)	5 (moderately positive)	6 (very positive)
Tonga	7 (very positive)	7 (very positive)	7 (very positive)	7 (very positive)
Vietnam	5.7 (moderately positive)	6 (very positive)	5.7 (moderately positive)	6.7 (very positive)

In the case of Kyrgyzstan, we can only hypothesize that negative scores may relate to a socio-cultural and socio-political environment where our respondent is in. Another hypothesis relates to the capacity of the disabled people's organizations and the civil activism climate in that particular country. The negative scores may also be caused simply by the fact that current practice of disability research in Kyrgyzstan is not designed for advocacy or service improvement purposes. In some studies, disability research can empower disabled people (Nasir, Efendi & Hussain 2019; Nasir & Hussain 2019) while others find it difficult to assess the empowerment effect of disability research (Oliver 1997). Data from Table 2 above also show varied average scores from all countries, signaling that empowerment effects must be contextualized and should not be commodified.

Secondly, we want to get feedback from our respondents whether they feel that disability research does bring positive change into their lives. The result shows that respondents from Brunei and Kyrgyzstan do not feel that disability research can bring positive change to disabled people's lives. This may cause by the research practices in those countries that only aim to meet meritocracy as abundantly criticized by previous studies (Barnes & Mercer 1997; Kitchin 2000; Nasir & Hussain 2019; Shakespeare 1996). From another angle, these results may also cause by respondents' own belief that research only exists for academic purposes and does not have relation to social life.

Table 3: Change production from disability research

Country	Average point
Bangladesh	7 (very positive)
Bhutan	5.5 (moderately positive)
Brunei	3 (least negative)
Fiji	7 (very positive)
Indonesia	4.3 (least positive)
Kyrgyzstan	1 (very negative)
Laos	7 (very positive)
Malaysia	5.3 (moderately positive)
Mongolia	4 (least positive)
Myanmar	6.3 (very positive)
Nepal	7 (very positive)
Philippines	6.6 (very positive)
Samoa	7 (very positive)
Sri Lanka	5 (moderately positive)
Tajikistan	7 (very positive)
Tonga	7 (very positive)
Vietnam	6.3 (very positive)

The response by Brunei in Table 3 above contradicts the positive response in Table 2 and Table 4 below which the respondent from Brunei rates negative in terms of the tendency for exploitation among local researchers. To bring positive changes in disabled people's lives and society, besides reforming the disability research praxis, the translation of research findings to practical solutions also necessitate political will and civic consciousness (Nasir & Hussain 2018). This is where the leadership of disabled scholars and disabled leaders in the region play a significant role.

The change production of disability research also relies enormously on several other factors such as the collective understanding of change and its processes, the recognition and capacity among researchers and the disabled community to transform knowledge to practices and solutions, and the power possessed by disabled activists and disabled people representatives at the policymaking table.

Thirdly, we also want to investigate whether our respondents view that researchers have a high tendency to exploit disabled people. Respondents from Indonesia, Laos, Mongolia, and Samoa do feel that researchers have a high tendency to exploit disabled people.

Table 4: Negative exploitation by researchers

Country	Average point
Bangladesh	1 (very negative)
Bhutan	1.8 (very negative)
Brunei	1 (very negative)
Fiji	1 (very negative)
Indonesia	4.7 (least positive)
Kyrgyzstan	2 (moderately negative)
Laos	4 (least positive)
Malaysia	3 (least negative)
Mongolia	4 (least positive)
Myanmar	1 (very negative)
Nepal	1 (very negative)
Philippines	2.1 (moderately negative)
Samoa	5 (moderately positive)
Sri Lanka	1.5 (very negative)
Tajikistan	1 (very negative)
Tonga	1 (very negative)
Vietnam	2.7 (moderately negative)

Responses from four countries above echoes the findings in previous studies (Duckett & Pratt 2001; Kitchin 2000; Nasir, Efendi & Hussain 2019; Nasir & Hussain 2019). We do not deny that the interests shown by researchers in this region in doing disability research should be praised. However, it is imperative that we also recognize that disability research or disability issues for that matter requires different epistemological and ontological basis (Barnes & Mercer 1997; Hughes 2007; Morris 1992; Oliver 1992, 1997, 2002; Stone & Priestley 1996; Zarb 1992). We should also continuously reflect on the way we conduct such research and what change we can bring from it.

That is why we propose that disability research production, as recognized by previous scholars, should employ the emancipatory paradigm. To put it simply, emancipatory paradigm concern with the translation of research findings into practical measures either in a form of policy, program or skill development among disabled persons. Not saying that the emancipatory disability research model is perfect (Barnes 2003; Barton 2005; Danielie & Woodhams 2005; Freedman 2006; Watson 2012). But,

researchers must have a clear intention and interest to bring change to disabled people's lives through their research while being mindful of the issues related to the internal and external structure of a research production (Nasir & Hussain 2018).

Finally, we ask our respondents whether they see a need for collaboration between different stakeholders in conducting disability research. Besides Kyrgyzstan, all countries score positively for this final question. As we hypothesized before, the negative response by Kyrgyzstan may be related to its socio-cultural and socio-political environment. Nonetheless, there exists a good orientation for the co-production of disability research projects in many countries in the Asia-Pacific region.

Table 5: Need for collaboration between different stakeholders in disability research production

Country	Average point
Bangladesh	7 (very positive)
Bhutan	6.5 (very positive)
Brunei	7 (very positive)
Fiji	7 (very positive)
Indonesia	7 (very positive)
Kyrgyzstan	3 (least negative)
Laos	7 (very positive)
Malaysia	6 (very positive)
Mongolia	7 (very positive)
Myanmar	7 (very positive)
Nepal	7 (very positive)
Philippines	6.7 (very positive)
Samoa	7 (very positive)
Sri Lanka	5.5 (moderately positive)
Tajikistan	7 (very positive)
Tonga	7 (very positive)
Vietnam	6.7 (very positive)

Watson (2012) and Shakespeare (2014, 2015) call for a critical realist agenda of disability research and disability studies to revitalize the intellectual and political aspirations of this discipline. The following section outlines our proposal on the basic framework for a critical realist disability research which draws on the neo-biopsychosocial model of disability (Nasir & Efendi 2018).

#### OUTLINING FUNDAMENTAL CRITICAL REALIST DISABILITY RESEARCH FRAMEWORK

In this section, we propose the basic facets which one must consider and embody when conducting disability research from the standpoint of critical realism. First, as we advocate for three basic characteristics of disability model or theory, we too postulate the same characteristics also applied to critical realist disability research. Those characteristics are clear operationalization of the terminologies or concepts used, a clear explanation of the dynamics of and relationships between concepts, and offer possible practical solutions to disabled people's struggles (Nasir & Efendi 2018, p. 28). This calls for the embodiment of emancipatory-inclusionary intention and one must also immerse oneself into the topics, including familiarizing oneself with a broad epistemological, theoretical, and methodological frameworks (Nasir & Hussain 2018, p. 46).

One must also recognize and apply six principles of the basic theorem of disability which are interrelatedness, intersectionality, diversity, the notion of change, universalism versus specialism, and optimistic/realistic idealism in their research topic (Nasir & Efendi 2018, p. 29). Considering these principles not only just promote a plurality of theories or research methods, but acknowledge the existence of knowledge at different layers of social structure, including within the researchers themselves (Tregaskis & Goodley 2005, p. 367; Nasir & Hussain 2018). Reflexivity must also be an inherent part of one's thought and research process (Barnes & Mercer 1997; Nasir & Hussain 2018, 2019; Oliver 1997; Shakespeare 1996, 1997).

Without religiously attaching oneself to a particular theory or model (Danielie & Woodhams 2005; Hughes 2007; Morris 1992), we must also recognize the continuous multi-relational interactions between the domain of self, society, and environment (Nasir & Efendi 2018). Such a consciousness helps us to identify and interrogate the overarching system of disablement, rather than perceiving disablement as a mere negative transactional relationship between the disablers and the disabled (Nasir & Efendi 2020).

#### CONCLUSION

In conclusion, the results show that all countries in the Asia-Pacific region, except for Kyrgyzstan with respect to advocacy and service improvement, have a positive attitude towards and view disability research as a useful instrument for policy formulation, advocacy, service improvement, and disabled people empowerment. On the contrary, respondents from Brunei and Kyrgyzstan do not feel that disability research can bring positive change to disabled people's lives. Research participants from Indonesia, Laos, Mongolia, and Samoa also feel that researchers have a high tendency to exploit disabled people.

We recognize further research is urgently needed which draws and triangulates qualitative data from different stakeholders (e.g. policymakers, policy implementers, local academics, local disabled leaders and activists, international bodies, etc.). We also



recognize the present article can only supply very superficial data on the topic, hence these findings must not be generalized. We urge regional bodies such as the Economic and Social Commission for Asia and the Pacific, besides focusing on the collection of reliable and comparable data on disabled persons, to conduct disability research impact assessment through cooperation with national organizations of or for disabled people and governments in the region.

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