

ASSESSING THE SITUATION OF DISABILITY RESEARCH IN THE PHILIPPINES: AN EXPLORATORY STUDY

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ABSTRACT

This paper attempts to discuss findings from an exploratory study in respect to the situation of disability research discourse in the Republic of the Philippines. We disseminate qualitative surveys to three key informants in The Philippines that we choose purposively. The three informants consist of a person with visual impairment, a person with speech impairment, and a person with mobility impairment. Responses from our informants reveal there exists a priority gap on disability research production between different stakeholders. We also learn that disability research produces benefits both in micro and macro contexts. Informants also claim to face barriers in accessing local disability research. Concerns are also being made in regards to emancipatory impact of local disability research as well as for competency and commitment by local researchers. We conclude this paper by stressing the importance of disability studies scholarship development in Southeast Asian region and aggressive effort is needed to merge the academic, political and public spheres to empower the disabled community.

Keywords: Disability research, disabled community, exploratory study, research impact, the Republic of the Philippines.

INTRODUCTION

The importance of data collection on disabled people should not only be viewed to identify the prevalence or number of disabled people in a particular geographical setting, rather data on disabled people should also represents many aspects of their lives for policy, programme, and service development. Under sub-article 1(f) of Article 4 in the Convention on the Rights of Persons with Disabilities, the signatory state party must:

“... undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines” (United Nations, 2006).

Under the same convention, Article 31 dictates the state parties to collect data for policy formulation, to assess the state parties’ achievement in fulfilling their duties under the convention as well as to disseminate the data collected to disabled people and other relevant entities (United Nations, 2006). This shows the importance as well as the benefits of conducting research on disability issues. In short, disability research can be used for development, monitoring, and evaluation purposes.

With that aspiration in mind, we are curious whether such discourse is happening in Southeast Asia region. Thus, we conduct this exploratory study to investigate the situation of disability research in this region, focusing on the Republic of the Philippines. Findings from other Asian and the Pacific countries including Malaysia are discussed elsewhere (Nasir, Efendi, Lau & Wong, 2019a, 2019b; Nasir & Hussain, 2019).

This study is conducted to achieve three main objectives: (i) To assess the current development of disability research in the Philippines; (ii) To explore local disabled people's attitude toward disability research; and, (iii) To analyse the challenges relating to local disability research production. In the next section, we present the snapshot of disabled people's situation in the Republic of the Philippines. Then, we briefly discuss disability research trend in Southeast Asia region after the enforcement of the Convention on the Rights of Persons with Disabilities. Following that, we explain the methodological process that we choose for the purpose of this study. Lastly, we discuss the findings from the responses from local informants.

OVERVIEW OF THE DISABLED COMMUNITY IN THE PHILIPPINES

It is not an exaggeration to say that the Republic of the Philippines is among the earliest country in Southeast Asian region to have a specific law on disabled people which is called "Magna Carta of Disabled Persons" (Republic Act No. 7277). The act is approved in 1992. This act entails all general provisions for disabled persons in the Republic of the Philippines. Besides that, there is also Republic Act No. 10754 which aims to extend the privileges for disabled citizens among others legislations.

A survey by Economic and Social Commission for Asia and the Pacific (2012) reports a total of 942,098 disabled persons in the Philippines with the disability prevalence of 1.2%. Three years later, the number increases to 1,442,586 with the percentage of disability prevalence of 1.6% (Economic and Social Commission for Asia and the Pacific, 2016). The government of the Republic of the Philippines signs the Convention on the Rights of Persons with Disabilities in 2007, then ratifies the convention in the following year (Economic and Social Commission for Asia and the Pacific, 2012).

In addition to the abundance of legislation either develop for specific or include the interests of its disabled citizens, the government of the Republic of the Philippines also develops Plan of Action for the Decade of Persons with Disabilities 2003-2012 as well allocates 1% from the total agency budget to implement programmes for disabled people in the country (Economic and Social Commission for Asia and the Pacific, 2012). In employment aspect however, the data is not available (Economic and Social Commission for Asia and the Pacific, 2016) and this may cause by unsystematic or lack of comprehensive data collection at national level.

Like in other Southeast Asian countries, disability issues are getting more attention by the government of the Republic of Philippines. From data presented above, it is reasonable to argue that more data collection must be made on disabled people's lives in all economic, social, cultural, and political spectrums. Therefore, disability research is the key tool that can be used by both government and the Disabled People's Organisations to gather such data. In the next section, we take a sneak peak on how the disability research progressing in the Southeast Asian region in overall.

DISABILITY RESEARCH IN SOUTHEAST ASIA IN POST-CRPD ERA

To date, as our research goes, there is no official platform for database on disability research in Southeast Asian region under ASEAN. During the period of this paper is written, ASEAN Intergovernmental Commission on Human Rights (AICHR) takes the responsibilities in spearheading the regional action on disability issues, which is now known as the ASEAN Enabling Masterplan 2025: Mainstreaming the Rights of Persons with Disabilities. As of now,

there is no special establishment under ASEAN that caters and monitors disability issues in this region, nor there is a special rapporteur on that matter.

Recently, ASEAN members adopted the ASEAN Enabling Masterplan 2025: Mainstreaming the Rights of Persons with Disabilities. In this regional framework, there are few key actions link to research and data collection for the benefits of disabled community in the region. For instance, Key Action 7.5 under the ASEAN Political-Security Community (APSC) pillar outlines the following:

“Enhance cooperation between ALAWMM and ALA and other Track II organisations including organisations of persons with disabilities, through seminars, workshops and research on international law, and application of international conventions such as CRPD to national legal frameworks”

Another example is Key Action APSC 16 which outlines:

“Support an effective coordination mechanism among ASEAN sectoral bodies, national statistical ministries/institutions, and local communities that will focus on gathering and disseminating reliable, coherent, and comprehensive statistics on persons who are often greatly affected in disaster situations such as children, women, elderly/older persons, and persons with disabilities to ensure that this information informs decisions on effective allocation of disaster preparation resources.

However, there are several regional entities that focus in few topics relating to disabled people in Southeast Asia. Those entities such as ASEAN University Network on Disability and Public Policy (AUN-DPPnet) which its headquarter is located at the University of Malaya, Malaysia and the ASEAN General Election Network on Disability Access (AGENDA) which its headquarter is located in Indonesia. There is also ASEAN Disability Forum which serves as a platform for activists, scholars and other stakeholders exchanging knowledge and solutions.

Besides the regional entities mentioned above, there are researchers who conduct disability research which focuses on the disabled people in this region. Those research include in education aspect (see for example Lay & Hui, 2014; Nasir & Efendi, 2016; Siska, 2015), disabled women’s issues (for example Efendi, Fadzil & Khoo, 2018; Xuan, Mitchell, de Lange & Fritsch, 2015), intellectual disability (for example Soltani, Roslan, Abdullah & Chan, 2012), health care (for example Nualnetr & Sakhornkhan, 2012), early intervention and detection (for example Kuipers & Maratmo, 2011) and community-based rehabilitation programme (for example Magallona & Datangel, 2011).

However, further and more comprehensive audit must be done in this area in order to study the progress and coverage of disability research which has been done in this region before and after the formulation of the Convention on the Rights of Persons with Disabilities. Nevertheless, we can see the potential of disability research sector in this developing region. The following section discusses the methodology that we employ for the purpose of the current study and we continue with the discussion on the data collected.

RESEARCH METHODOLOGY

For the purpose of this study, we employ exploratory qualitative research design. We extract qualitative data from local informants. We choose this design to understand, explore, and make sense of the situation of disability research in the Philippines. We design a qualitative survey which contains 20 open-ended questions using Microsoft Word application. Through the survey, we ask a range of questions, from the perception towards disability research by different interest groups, the benefits of disability research, access to local research, research ethics and

methodology, the role of disabled and non-disabled researchers as well as the possibility of research collaboration in local setting.

The survey is written in English language. After getting the agreement from the local informants to participate in the study, we send the survey to their email addresses which they provide. The informants answer the survey by typing in their response in the answer section. Then, our informants reply our email along with their responses. When we are unclear with their answer or need further explanation, we use Facebook chatroom to send our follow-up questions.

Three local informants take part in this research; Sternfield, Manwell, and Csandra. They are the citizens of the Republic of the Philippines. All three of them have some form of impairment. Sternfield, a person with visual impairment, is currently working as lecturer, researcher, disability rights advocate, and public policy consultant. He involves in many consultancy work with local non-governmental organisations and government agencies with his focus area on information and communication technology (ICT) as well on accessibility issues for blind people in his country. He has past experience as research participant in many topics such as inclusive education, ICT, employment and accessible transportation. He himself has experience in conducting research relating to disabled people in many areas including leadership in inclusive education, government's perception on inclusive education as well as disability policy analysis.

Manwell, a person with speech impairment, is currently working as electrical engineer. He has Master Degree in entrepreneurship and currently taking his second Master Degree in political science. He also has past experience as research participant in studies on livelihood and employment for disabled persons. Furthermore, he has experience in developing a research proposal on political participation of disabled people.

Csandra, a person with mobility impairment, is working as programme associate in an institute which focuses on disability and public policy. She previously did her Master Degree in international affairs with a major in comparative disability policy. As a programme associate, Csandra has experience in working on many research projects. She also involved in many research as research participants. Those research include research on information technology for disabled persons and media portrayal of disabled persons.

These three informants are selected purposively through the contact and previous relationship built between the first author with them. Besides that, we choose them because of their active involvement in the local disability advocacy as well possessing high level of education. Their different background, plus the difference of the category of impairment they have, can offer a rich first look on the situation of local disability research discourse. We use thematic analysis technique on their responses. Three main theme emerge from the analysis; perception towards disability research, access to local research, and concerns about local disability research production. We do not use any analytical software. Rather, we only use Microsoft Word application to arrange and group the responses according to the themes.

The participation of the informants are voluntary and we do not offer any form of reward. First, we contact our informants to inform them about our intention and explain to them about the overview of the study. Then, we ask them for their participation. After receiving their agreement, we ask for their email addresses. In the survey file, we provide them with all relevant details about the study; research title, corresponding researcher, research objectives, and research method. To guarantee our informants' anonymity, we assign pseudo-name to each of them.

As for the data reporting, we follow the advise and principle of data reporting as first author emphasised in his previous work (Nasir & Hussain, 2018), which we share the unpublished final report of the study for their personal keep and reference. At the very least, we are hopeful that this research sharing can support local advocacy and empowerment efforts.

FEEDBACK FROM LOCAL INFORMANTS

We divide this section into three subsections; perception towards disability research, access to local research, and concerns about local disability research production. This simple yet critical findings are vital to explore the situation of local disability research discourse, not only in the Philippines, but also reflect the general take on such discourse in ASEAN region context. However, we have to note here that although we receive responses from persons with impairment in the Philippines, these findings cannot be generalized to present the whole disabled community in the country since these findings are from individuals' feedback based on their own perception and experience in the field. Despite its obvious limitation, we view this study as capable to set the stage for critical discussion for disability research discourse, both for local level and the regional level.

i) Perception Towards Disability Research

All three informants claim that disability research is progressively developing in their country. This positive development is due to the actions which has been taken up by various parties, both government, non-government and academic institutions.

"I think more and more individuals and groups are becoming interested in disability and inclusion research primarily because of the advocacy work of various disabled people's organizations, local and international non-profits, and some government agencies. Also, universities and the academe have always been active in conducting disability-related studies although limited to a few areas." (Sternfield, 17 August 2017)

As pointed out by Sternfield, Manwell also state the links between the efforts from advocacy groups with the increasing implementation of disability research in the Philippines.

"To my perception, disability study may be growing in the Philippines as more and more disability rights advocates come out and advocate for PWD rights." (Manwell, 17 August 2017)

As for Csandra, she argues that the increase in number of disabled population in her area is one of the factors that lead to heightening interests and needs for conducting disability research.

"Yes, In my City alone as a Focal Point from 2013-2016 the PWDs data rises from 700 to 1400 plus due to the inclusion of Senior Citizen with Disability and Children with Disability." (Csandra 20 August 2017)

From the responses above, it signals a positive encouragement for local disability research as part of practice in the country. As outlined in the Convention on the Rights of Persons with Disabilities, the informants too see the benefits of disability research for advocacy and policy planning purposes.

"Disability research, especially those involving quantitative methodologies are indeed useful. Data provides justifications. ... Disability research is vital to policy formulation..." (Manwell, 17 August 2017)

"Yes, of course. Having data makes the advocacy more potent. Having data convinces legislators and policy makers to take notice of our causes. It also helps the public to be aware of issues in the disabled community in the country. Research also helps develop disability discourse in the country and opens the opportunities for academic discussion on various

disability-related topics. ... Research is useful for the whole policy cycle. Data from research helps set the agenda. Data helps policy makers to come up with creating strategies and well-grounded policies. Data helps in improving processes and practices as well as assessment mechanisms.” (Sternfield, 17 August 2017)

However, Csandra also points out that in order for a policy or programme to work, continuous and effective implementation in all levels by all parties must be ensured.

“Of course ... It is vital for any planning or implementation to have a solid foundation on the Policy but it must be synchronized in such a way that it would work.” (Csandra, 20 August 2017)

Although the increasing number of disability research conducted in the Philippines seems promising, the informants claim that there is a priority gap between different stakeholder groups.

“As a whole, I would say no. The government does not consider disability in general as a pressing issue. However, as mentioned, some government agencies are taking the initiative to partner with NGOs for research and other disability-related projects and programs. ... I think the local non-government organizations and disabled people’s organizations are the champions of disability research in the country. Having experience in working for NGOs, we see the potential of research for agenda-setting and to get the public’s attention on our advocacies.” (Sternfield, 17 August 2017)

Manwell shares the same opinion as Sternfield in this matter. He argues:

“Disability services, yes. But disability research may not be given enough attention.” (Manwell, 17 August 2017)

The policies, action plans and programmes developed at the national level may be the result of in-depth research on such issues, however the enforcement of such laws or policies, and the effective implementation of such programmes are very much depending on the attitude and capacity of local authorities. The emancipatory action may be stunted as Csandra points out:

“Yes in the National Level but in the local level and the City level the allocation of Budget for the Persons with Disability has not been set-up yearly but the local Social Welfare usually gave support.” (Csandra, 20 August 2017)

Finally, we also curious of our informants view on the impact of disability research on the empowerment of local disabled persons in their country. Our informants suggest that the impact of local disability research on the empowerment of disabled persons in the Philippines happen in macro dimension (indirectly to the disabled community) and micro dimension (directly to the disabled individuals). Manwell argues that:

“Yes. Evidence-based information is vital in policy development.” (Manwell, 17 August 2017)

Evidence-based policy development is vital to identify necessary actions and programmes to be enacted in order to empower the disabled community. From Manwell’s response, we can say his view is more towards top-down process of empowerment. Sternfield, however, has a unique take on this matter. To him, the empowerment is more at community level and personal level. Answering to this question, he writes:

“I think so. Research has influenced NGO’s to anchor their programs and services on solid data. Many of these are skills and capacity building programs which really do empower disabled persons. Also, some research projects employ disabled persons so they gain valuable work experience.” (Sternfield, 17 August 2017)

Disabled People’s Organisations can utilise research as a tool for them to identify the needs and interests of their members as well as to evaluate their capacity and achievements. Research projects that employ disabled individuals can also contribute to the human capital development as such experience can empower them in terms of skills and knowledge. As Oliver

(1997) points out, empowerment should be one of the principles in conducting disability research. Samah and Aref (2009) outline the central theme of empowerment as a form of:

“...process whereby individuals or groups are able to exercise their ability and capacity to understand, interpret the problems faced, and later define the needs, and to translate these into an action process by participating in organizing themselves to decide, influence, demand, negotiate and engage in carrying out activities”.

Generally, empowerment of disabled people are promoted and developed in at least five dimensions which are decision making, knowledge and skills development, participation, advocacy or voicing out, and critical consciousness. This suggests that disability research production may contribute to human capital and social capital of the disabled persons, thus opens up to a possibility of a nexus of socio-emotional and psychological relations of disability research production.

ii) Access to Local Research

The second aspect we want to investigate is the level of accessibility to local research. Access to such information not only vital for disability studies in academic sense, but also provide ample of facts and evidence for advocacy and development purposes. Unfortunately, all three informants face with serious scarce and inaccessible sources.

“It is not easy to find the correct statistics of disability in my country because a system is not really set up properly. Research materials are also available but I cannot find a one website which has it.” (Csandra, 20 August 2017)

It seems naturally unsurprising that the problem of inaccurate, insufficient or contradictory data often happens in developing countries. First, this may cause by the different definition used to identify the prevalence of disabled people in a particular country. Different definition can produce different result in terms of prevalence and category of people identified as disabled persons (Economic and Social Commission for Asia and the Pacific, 2012; Gronvik, 2007, 2009). Different government agencies or ministries may use different definition of disability. Failure to have definition standardization can cause further confusion and unsound result. Secondly, even if the responsible government agencies has a specific database on disabled people, it may not publically accessible and there maybe no coordination or mechanism in place to capture the real time data on disabled people across different agencies.

For Manwell, he finds it very difficult to find latest research. Either for academic or advocacy purposes, it is vital to have the latest research on a particular issue. The scarcity of local research can be explained in three different angles: (i) Most local research are not published, either as journal article or books; (ii) The research findings are published in journal that do not provide online open access services; or maybe, (iii) It is not a common practice for the researchers or organization to disseminate or share their findings with public through accessible platform.

Being a lecturer and a public policy consultant, Sternfield has a slightly different view on the matter.

“If they are on peer-reviewed journals, yes [it is easy to find]. Otherwise, many of the research, especially those conducted by NGO’s are not widely circulated. Some of them may be found in libraries but often, many of them have gone out of print and are very difficult to find. Fortunately, many NGO’s give copies of the research to professionals and academics who want to use them for their studies or work.

This situation may also contribute to the worsening disconnectedness, either between fellow academics and university students as well as between the academia and public sphere.

Looking at the responses above and referring to informants own suggestions, it is time now to establish a centralised database of research reports and articles as well as policy papers and guidelines which are publically accessible to all. Such endeavour should not only be implemented in the Philippines, instead other Southeast Asian states must undertake the same action. Malaysia, for example, has established a database of local disability research which is called Clearinghouse for Research on Disability since 2011 under the responsibility of the Institute of Public Health, Ministry of Health Malaysia.

iii) Concerns about Local Disability Research Production

The third aspect is to explore other concerns among our informants with regards to local disability research production. Sternfield shares his concern on the research outcome or research findings that are not shared by the researchers, which echoes the same findings in previous studies (Duckett & Pratt, 2001; Kitchin, 2000; Nasir & Hussain, 2019).

“Sometimes, especially student-led researches tend to exploit disabled persons but not follow-up when the study is finished. Also, many researchers just use the knowledge, skills and experience of the disabled community and often keep the data they gathered unused. ... Also, data generated from schools and universities are often not shared with the disabled community.

Understandably, the absence of change idealised by the disabled community through research surely causes them to feel very frustrated. It seems that the practice of “stocking up the research onto the library shelves” becomes as academic habit and it is counter-productive. It symbolises a meaningless participation of disabled people in such discourse. This is very worrisome since the same failure of previous research on disability issues as Oliver (2002) raised up many years ago is still happening. For that, Sternfield urges that:

“... there must be a guarantee that the research data will be shared and used with the disabled community.” (Sternfield, 17 August 2017)

In addition to the challenge mentioned above, there are also concern about the level of researcher’s competency and the existence of interest. On this point, Manwell shares his opinion by writing:

“... Competency as well as interest to conduct such [research] may be lacking.” (Manwell, 17 August 2017)

Researchers, either disabled or non-disabled, must possess the proper ontological and epistemological orientation as well necessary skills and knowledge to conduct disability research effectively. As first author points out in his previous work (Nasir & Hussain, 2018), researchers must adopt proper research ethics, ensuring the accessibility of the method used, building relationship and sharing research findings with the researched group. With regards to research interest, researchers must have a clear goal to bring emancipation to the lives of his or her research participants. But first, as Manwell’s said, the challenge of lacking interest in researching disability issues must be overcome. The rise and the merge of intellectual and political discourse in disability movement still needs nurturing and continuous promotion.

An article by Ryser, Markey and Halseth (2013) offers a valuable guidance in developing curriculum and research opportunities which rooted in community engagement. The same lessons and experience can be adopted in nurturing interests and promoting disability studies. Initially, we need to have a primary group of dedicated people, both graduate students and academicians who will start the movement. Here, activists and writers among disabled community can play their role in raising consciousness on disability issues.

CONCLUSION

Even though there is positive development in local disability research production, we can see that there exists priority gap between government and Disabled People's Organisations. Informants also report on the lack of access to local research. Echoing the findings of past research, informants are concern about the emancipatory impact of research which has been done and the level of competency and research interests among local academics. Insights from this study prove that further exploration on local disability research production should be conducted. Such exploration should not only concerns with the ontological, epistemological and methodological aspects of disability research production, in fact it should also investigates the attitude among policy makers and policy implementers toward the significance of disability research, as well as the cultural and geographical factors, which can lead to the potential of institutionalising the disability studies in local context.

A wider study should also be considered at the regional level. The findings from such research can set the fundamental basis for an establishment of better mechanisms in regional planning, coordination, monitoring, and evaluation purposes. In our opinion, ASEAN as a community in this region, has the market potential for inclusive development projects and programmes. Thus, the scholarship in disability studies in this region should be developed to meet that market. We also suggest that a regional database on disability research must be established. This can be materialised when there is collaboration at regional and national level between governments, research institutions, Disabled People's Organisations, and other civil society organisations as the way forward to systematically remove all barriers to full and effective participation of disabled persons across economic, social, cultural and political dimensions.

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