

Documenting the Challenges of Conducting Research on Persons with Disabilities (PWDs): Sharing Experiences and Suggestions to Ponder

¹Che Su binti Mustaffa, ²Haslina binti Halim, ³Jasni bin Ahmad, ⁴Nurul Aina binti Johari, ⁵Mawar Qadijah binti Ishak

¹²³Universiti Utara Malaysia

⁴Albukhary International University

⁵Kolej Komuniti Bayan Baru

¹²³{chesu402; lina; jasni}@uum.edu.my,

⁴nainajohari99@gmail.com,

⁵mawarqadijah@gmail.com

ABSTRACT

As can be inferred from literature reviews across the globe, research on people with disabilities (PWDs) are growing tremendously over the years. Although the number of research on PWDs is increasing, little is known about the challenges experienced by researchers in the field. Given the under-studied and limited published research on PWDs in Malaysia in comparison to other studies conducted in the western arena, especially on the challenges faced by researchers, efforts must be intensified to produce more researchable and publishable issues on PWDs. Experiences and suggestions are shared for the community and academics to ponder upon, and act accordingly so that the well-being and potentials of PWDs can be further explored. The discussions presented in this paper result from the experience of doing fieldwork while conducting applied research on creating sustainable livelihood opportunities for all PWDs in the B40 group in Baling district. The main purpose of this paper is to discuss the challenges faced by the researchers in conducting research on persons with disabilities. The challenges we faced while conducting the interviews are broken down into several categories, namely the respondents themselves, family members, communication challenges, expectations of the respondent, and the ability and capability of the researchers themselves. The reflections discussed in this paper will assist future researchers to be more aware of the potential challenges they might encounter in the field of a similar low resource settings while conducting research among marginalised population groups, such as persons with disabilities.

Keywords: *People with Disabilities (PWDs), social norms, stereotypes, qualitative, Malaysia*

1.0 INTRODUCTION

A good number of studies (see for example Gilbert, 2004; Leach, Parker, MacGregor, & Wilkinson, 2020), on various issues related to disability can be found in the literature. However, research related to sensitive topics such as employability, entrepreneurship, dependency, human rights of persons with disabilities are limited in number. The challenges of getting a good quality database to access persons with disabilities has been documented by many authors in the past. Robson and Evans (2020) in a comprehensive review of international data sets of developing countries mention that existing data sets are fragmented most of the time, even the definition of disability is inconsistent. PWDs or handicapped are referred to those who have physical, mental, and sensory limitations (Halid, Osman & Abd Halim, 2020).

Hence, this paper shares some of the challenges experienced by the researchers while conducting the research on employability and entrepreneurship among persons with disabilities in Baling, Kedah, as well as the strategies adopted to resolve those challenges. The reflections discussed in this paper will assist future researchers in understanding potential field challenges they might encounter in similar low resource settings while conducting research on employability among PWDs. The learnings from these challenges and the insights presented in this paper will appease future researchers to be aware of those challenges and get prepared beforehand.

2.0 CHALLENGES EXPERIENCED BY THE TEAM

This section highlights the challenges that the research team experienced during the data collection process. The challenges are discussed from seven perspectives, which include the difficulty to reach the respondents and obtain an informed consent, difficulty to maintain privacy, difficulty to explore sensitive issues on employability and future,

communication barriers, building trust, pandemic COVID-19 and ethical issues.

2.1 Difficulty to Reach the Respondents and Obtain an Informed Consent

Issues of accessibility and inclusive participation of PWDs continue to become an utmost area of concerns. Locating PWDs especially in rural and remote areas was a challenging task for the researchers. In identifying persons with disabilities, the researchers utilised the information obtained from the Research Assistants before the actual fieldwork took place. Issues arose when the list was not comprehensive, and contained inaccurate information of PWDs. For example, full address or contact information were sometimes missing, as these were not being updated regularly. As a repercussion, sometimes reaching out to a respondent in a certain locality became very difficult. To mitigate these challenges, the lists provided by the research assistants were cross-checked with local opinion leader and necessary corrections were made. While accessing persons with disabilities for interview, at times we found that the information available in the database was not correct and the list had not been updated regularly. The final part was the environmental challenges, which were linked to the struggle of researchers in getting accessed to PWDs.

2.2 Difficulty to Maintain Privacy

Maintaining privacy during the process of data collection was one of the major challenges encountered by the research team. As mentioned earlier, many of the respondents relied on family members in performing their daily tasks. For those respondents, the caregivers or family members were around most of the time, and therefore the respondents did not have much privacy to communicate and express themselves. The sensitive nature of the questions in the study required privacy and when the researchers requested the PWDs to answer by themselves

such as questions about their attitude, social norms or stereotyping that they had experience, they were not able to respond or share the information due to the interference from family members or care takers. As PWDs are considered vulnerable to discrimination and abuse, often the family members did not feel comfortable to allow the researchers to talk to them privately. To mitigate this challenge, interview process and the study objectives were explained to the parents/caregivers in detail and permission was sought to conduct interview. The researchers tried their best to ensure privacy and security of the respondents while collecting data from them.

2.3 Difficulty to Explore Sensitive Issues on Employability and Future

As have been expected most PWDs in the B40 group had very minimal knowledge about entrepreneurship and displayed negative attitude towards it at times. In some locations of study, respondents or care givers were offended when they were asked about the future of PWDs under their care. Moreover, several respondents were reluctant to share their personal views, especially on stereotyping towards PWDs. In overcoming this challenge, the researchers started with building rapport and trust with the respondents in order to encourage disclosure of sensitive information. However, anyone uncomfortable or unwilling to disclose any information were not forced to do so since their participation in the study was on voluntary basis.

2.4 Communication Barriers

The major challenge experienced by the research team during data collection was communication difficulties in the form of interpreting verbal responses, lack of skills in sign languages when dealing with persons with sensory impairments and difficulties of the respondents to share their accurate views or perspectives due to limited cognitive ability. Persons with mild to moderate speech impairment or hearing impairment were

interviewed with an average level of difficulty. It was also found that respondents with hearing or speech impairment were not familiar with universal sign language. Instead, they communicate with personalised sign languages, which in most cases only the caregivers or close friends could understand. There were instances where the respondents wanted to say something but could not express themselves properly due to a communication barrier. In confronting the issue, the researcher had to modify and simplify the questionnaire and interview sessions. According to Gilbert (2004), the communication difficulties in conducting research on PWDs is inevitable. These obstacles might hinder researchers to fully understand the whole context of the information provided by the PWDs and the process itself was laborious.

In mitigating this challenge, assistance from the caregivers were obtained in the presence of the respondents. Furthermore, while interviewing persons with mild to moderate hearing impairment, researchers spoke loudly and slowly to allow sufficient time for the respondents to lip read. In addition, help from the caregivers was sought. In ensuring that the interviews were fruitful, researchers helped them understand the questions first, and then caregivers repeated it, and simplified in their own form of language so that appropriate response were obtained. However, persons with severe intellectual disability were not interviewed as they could not understand the questions nor did they respond. The different thinking process and understanding level enabled them to think intensively about various critical aspects and many a time they replied, 'I don't know'. In such cases, the researchers relied on the caregivers.

2.5 Building Trust

Another element that we found it essential when working with vulnerable populations, is trust building. In relation to this, we found that the transparency about the research project is an avenue towards building trust. Participants

have the right to be informed of the scope of the research, epistemology, methodology, procedures of recruitment, compensation, data analysis, decision-making processes, ethics, research dissemination, data confidentiality, consent, funding of the project, as well as the risks and benefits participants may face (Sinacore et al., 2019).

Trust is also built through relationships. In such a case, researchers might find themselves in multiple roles as they also became trusted community members. To mitigate these issues, the team tried to find certain support needed by the respondents such as the utilization of the Research Assistants who had been in the community for a while, opinion leader and initiating financial contribution such as zakat. Through these efforts we were able to build rapport and gained their trust.

2.6 Pandemic COVID-19

The COVID-19 pandemic that hit the world since 2019 has had unprecedented impacts on data collection process for this research. In response to the outbreak, physical distancing measures, national lockdowns and travel restrictions to control the spread of COVID-19 have been implemented in many states and districts in Malaysia including Baling, a place where the research team was supposed to collect the data. The inability to reach out to the respondents due to COVID-19 restrictions had significantly affected the data collection process, and yet, this was the crucial steps in this research.

Besides all these challenges, the team also found that some PWDS were able to utilised the Internet and other types of technologies at levels that were below those of the rest of the population. This was due to the lack of interest or education, but the technology and internet were unfriendly to people who experience various forms of disabilities. The barriers they faced were related to access and usage differ by type and extent of the disability a person has. Since the advent of the World Wide Web,

studies have shown the inaccessibility of web sites and additional elements of the Internet.

2.7 Ethical Issues

Evidence suggests that PWDs are not included in large-scale studies (Meyers & Andersen, 2000). Therefore, not explicitly making efforts to include PWDs potentially skews research findings. Even when universal design is applied throughout the research process, there may be times when accommodations are needed to enable equal participation for PWDs. Accommodations change how the task is accomplished so that respondents are able to participate in a task that they would otherwise be unable to complete. In other words, accommodations remove confounding influences of the assessment format, administration, or ways of responding. In this case, researchers must maintain the highest standards of ethics when working with human participants. For example, when a researcher is working with individuals from vulnerable populations, there is an additional ethical consideration to avoid the development or promulgation of a deficit discourse. In deficit discourse, the blame for a problem is situated with the person who is experiencing it. For example, women with obese bodies seeking reproductive health care are met with a narrative of blame for their body size, the belief that they are unwilling to moderate food intake and are generally lazy. Thus, in this research contexts, the researchers worked diligently to avoid the use of words that could hurt the respondent and researchers are also wary of the nonverbal aspects displayed.

3.0 LESSONS LEARNED: HOW TO OVERCOME THE CHALLENGES?

The experience we gained from the interviews in Baling, tells us that when it comes to disability, there is no one-size-fits-all solutions. Nonetheless, there are low-cost alternatives that can improve the overall level of participation. Here are some of the things that could be useful and should be considered when

conducting research involving PWDs.

3.1 Learn about the respondents or target group

An overview of the type of disability and some social variables is crucial to balance participants in focus groups, disaggregate data by categories, and prepare in advance for special requirements (for example, the use of a sign interpreter). It is also key to better understand power dynamics within the group. For instance, women face more discrimination than men, even if they have the same disability.

3.2 Be flexible during the interview process

PWDs are unique and they have different limitations. They also possess different sets of skills. Considering this, we can take advantage of the preferred method of communication and be open about the methodology we utilized in the research. For instance, the use of photographs can be considered as they have proven to be effective in communicating with participants with physical, hearing or development disabilities. This is an example of an alternative that requires small adjustments and can be easily triangulated with other methods.

One of the major challenges faced by the researchers while conducting interviews with PWDs is the communication difficulty. The challenge of the inability to express for persons with disabilities and the researchers' failure to use alternative methods of communication to establish a dialogue with PWDs who cannot communicate in a conventional way. New technologies such as speech generating devices can be used to communicate with people who have little or no functional speech to communicate.

3.3 Listen

There will be time when in experience doubt about certain issues concerning our respondents. When this happen, we can always ask the participants what are the things that could help make them feel more comfortable. In this case, participation is also about listening and learning

from others, and PWDs hold the key to understanding what suits them best.

3.4 Identifying key people

Collecting data from PWDs can be challenging, as we explained in the earlier section. We also found that having relationships with appropriate contacts can also make a difference in the approval process. Identifying key people early on and throughout the process will enhance the researcher's ability to think about the nuances of the study. Securing family members and caregivers as a guide during research was found to be useful and it helped the research team in accessing the respondents and get permission for the research.

3.5 Bear in mind the significance of the population that we are studying

The significance of the study is based upon the researcher's ability to demonstrate that the study is meaningful academically and practically, which will make it easier to secure support for the study and the data. Therefore, the researcher must remain clear about why this population is needed to investigate this specific research question. This is crucial as without their participation, our efforts are meaningless.

3.6 Strengths-based research approach

Researchers may also choose to use these six strategies in their strengths-based research approach: (1) include a focus on capabilities, strengths, and opportunities; (2) conduct research with and by instead of about the individuals or groups; (3) promote hope by using language that is person-centered and optimistic and leads to positive perceptions; (4) identify social context and the resources that exist in communities; (5) include research questions that lead to empowerment; and (6) engage research participants with respect, allowing opportunities in which they offer their own expertise about their situation.

3.7 Be mindfulness

Finally, as researchers, we also found that researchers should be mindful of measuring strengths, including promotive and protective factors, and considering culture and social ecology to provide a balanced and more accurate assessment while reducing researcher bias. Additionally, focusing on strengths provides a platform for meaningful intervention that is more personalized and empowering to the population of study. Interventions that are designed with and by the population of study and that include culturally relevant, feasible, and acceptable practices should be encouraged.

4.0 CONCLUSION

This paper discussed the challenges faced by the researchers while conducting research on PWDs. It also highlighted the strategies in minimising the challenges so future researchers could consider utilizing in the research project. The content of this paper delivers essential knowledge and insights required by future researchers who are going to conduct research on marginalised group, in a low-income setting.

5.0 ACKNOWLEDGEMENT

The authors would like to express a heartfelt appreciation and utmost gratitude to Yunus School of Business, Albukhary International University for awarding the research grant to carry out a study on PWDs.

6.0 REFERENCES

- Cookson, T., & Fuentes, L. (2020, May 9). Qualitative data is key to ensuring no one gets left behind by the coronavirus response. United Nations Office for the Coordination of Humanitarian Affairs (OCHA) News and Press Release. <https://reliefweb.int/report/colombia/qualitative-data-key-ensuring-no-one-gets-left-behind-coronavirus-response>.
- Gilbert, T. (2004). Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community*. Wiley. <https://doi.org/10.1111/j.1365-2524.2004.00499.x>
- Halid, H., Osman, S., & Abd Halim S., N., J. (2020). Overcoming Unemployment Issues among Person with Disability (PWDs) through Social Entrepreneurship. *Albukhary Social Business Journal*, 1 (2), 57-70.
- Leach, M., Parker, M., MacGregor, H., & Wilkinson, A. (2020). COVID-19—A social phenomenon requiring diverse expertise. *Social Science in Humanitarian Action Platform [Blog]*. <https://www.ids.ac.uk/opinions/covid-19a-socialphenomenon-requiring-diverseexpertise/>
- Meyers, A. R., & Andresen, E. M. (2000) Enabling our instruments: accommodation, universal design, and access to participation in research. *Arch Phys Med Rehabil*; 81(12): 55–59.
- Robson, C., & Evans, P. (2020). Educating children with disabilities in developing countries: the role of data sets 2003.
- Sinacore, A. L., Adekoya, I., Milani, A., Tomaro, J., Bu, S., Buchanan, J., Durrani, S., & Gescher, S. (2019). Methodological considerations when conducting research with vulnerable populations. *Proceedings from the 2018 Canadian Counselling Psychology Conference*, 133-147. <http://hdl.handle.net/1880/111416>