L-Università ta' Malta

Ethical Guidelines for Carrying Out Research with Disabled People

The present document complements the "Research Code of Practice" and the "Research Ethics Review Procedures" by providing further guidance regarding ethical issues in doing research which involves interaction with disabled people.

These can be downloaded from: https://www.um.edu.mt/urec

Background

Ethical issues in disability research go beyond ensuring that the disabled people participating in one's research do not encounter any risk or harm. It also involves being attentive to disabled people's perspectives and their concerns, and catering for their impairment-related requirements throughout the research process.

Emancipatory disability research has arisen from the disabled people's movement. It is intended to counter a long tradition of research in which disabled people are seen as passive objects of study whose lives are best understood not by themselves but by medical, educational, and other professionals.

The emancipatory research approach ultimately leads to a far more rewarding experience for the researcher and for the disabled participants. The following points are based on the principles of emancipatory disability research as set out by Stone and Priestley (1996)[1] and Barnes (2002)[2]. These points provide the researcher with practical guidance for ensuring that the involvement of disabled

[1] Stone, E. & Priestley, M. (1996). Parasites, pawns and partners : disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47(4), pp. 699-716. http://eprints.whiterose.ac.uk/archive/00000927/

[2] Barnes, C. (2002). 'Emancipatory disability research': project or process?. Journal of Research in Special Educational Needs, 2(1), no-no. https://doi.org/10.1111/j.1471-3802.2002.00157.x
(The public lecture on which this article is based is available at https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-glasgow-lecture.pdf)

people in their study takes into account the relevant ethical considerations throughout the research process.

A. Ensuring Access for All

These are practical tips to help you ensure that when carrying out your fieldwork, you provide access for all your participants. These are general guidelines and would need to be adapted according to the needs and preferences of the disabled participants:

1. Venue: when the research involves direct contact with research participants, such as interviews or focus groups, ensure that the venue chosen is accessible to all, unless it has been chosen by the disabled persons themselves. The Access for All Regulations provide details about physical accessibility. The most important points to keep in mind are:
    - The entrance to the venue is step-free or has an adequate ramp.
    - The room where the interview or focus group will take place is barrier free, and the width of the door is wide enough for a power wheelchair to go through (at least a width of 90cm). If there is a lift, there are no steps leading to the lift and the lift is big enough to accommodate a person in a power wheelchair. The lift should be 1.1m wide and 1.4m deep where the lift contains one door or has doors which are facing each other; or 1.4m wide and 1.6m deep where doors are located 90 degrees relative to each other.

- If the interview or focus group will take long, there are accessible sanitary facilities nearby.
- The venue should be free from excessive noise and lighting, and its design should not include busy patterns and clutter.

2. Transport: for some disabled people, actually getting to a venue where a research activity will take place can be problematic. For example, when conducting a focus group in a venue of your choice, make sure that no disabled people miss out on participating because they have no means of transport to and from the venue.
    - If necessary, offer to provide transport yourself. This may entail expenses which need to be factored into the research plan.
    - If disabled people will be arriving with their car, make sure that there are reserved parking bays for disabled people close to the venue.
    - Find a venue where the main entrance is suitable for all.
3. Carrying out online interviews and focus groups can be a viable option for disabled people. However, there are additional considerations to take into account. Some persons may not have access to a device which is connected to the internet. Others may not be able to connect from a room where they have privacy. Some persons may also have difficulties using certain applications or might not have access to applications at all. Please consider such issues and

ethical concerns when planning your research and address appropriately with your participants.

4. Access to spoken communication: people who are deaf or hard of hearing may use different modalities to communicate. Make sure that you find out what these are so that you can make the necessary arrangements.
    - If the participant uses Sign Language, arrangements should be made to book a sign language interpreter, according to their language of choice. The interpreter's availabilty would need to be take into consideration when deciding on the logistics. Aġenzija Sapport provides such services for free. If the person relies on lip reading, ensure that the venue is well lit and that there is no bright light directly in your face or behind you. Also make sure that you do not cover your mouth while speaking. The same applies if you are communicating online.
    - If the person uses an assistive listening device, take time to learn how they use it.

5. Use of communication aids: if the disabled person uses a communication aid, an assistive, an augmentative, or alternative means of communication, take time to learn how they use it. The use of communication aids can sometimes be time-consuming. Make sure you factor this into your research timetable.

6. Access to printed communication: information sheets, consent forms, questionnaires, dissemination documents, debriefing documentation, and other texts related to the research should also be accessible to all.

    - All documents should be written in a reader-friendly font. Whilst there is no single font which is best for all, there are a number of fonts which tend to be more reader-friendly, such as Calibri (which the University of Malta has chosen to use), Arial, Verdana, Tahoma, Helvetica, Century Gothic, Antigua, and others. The least reader-friendly font is Times New Roman, due to its regularity of lines, and should always be avoided. For some readers, Sans Serif fonts (Calibri, Arial, Verdana, Tahoma, Helvetica) may also be easier to read. Ideally, the text should be presented in such a way that the reader can change the font, the font size, and the background to their preference.

      The font size should not be smaller than 11; with a 1.5 line spacing and the text should be left-justified. This makes it more reader accessible (such as people with visual impairments and people with specific learning difficulties, developmental language disorder (DLD), or acquired language disorders). Researchers should ensure that the format used in written text is suitable for the specific needs of participants, depending on their particular impairment. These

reading accessibilities are also embraced by the EU law, after its accession to the Marrakesh Treaty.

- Child-friendly versions should be produced if disabled children are involved as research participants. The Save the Children Fund has produced guidelines on producing child-friendly documents.

- People with intellectual disability and reading challenges need all documents to be available in easy-to-read formats. Inclusion Europe has produced guidelines on how to write in this format. See also the easy-to-read information letter and consent form on the SWBFREC website.

6. Electronic material must be accessible for people with visual impairments. For example, a word document which is converted into PDF format is accessible, but a hard copy which is scanned as a PDF is not accessible because the computer reads it as an image and the document therefore cannot be read to the user by computer software. If you are using an online survey, it is important to ensure that it is accessible for people with visual impairment. Online questionnaires are generally accessible. However some question formats, such as the grid in Google Forms, are not. For further information about IT accessibility, you can see the resources of the Global Accessibility Awareness Day.

7. Disabled persons may have other impairment-related requirements which are not mentioned in the points above. Ensure that you provide them with the opportunity to identify these requirements and discuss them with you if necessary, so that you can make any necessary arrangements.

B. Sensitivity to Disabled People's Issues

These points will help you ensure that, in all phases of the research, you are sensitive to disabled people’s needs and that you take their concerns into account:

1. Use of language: it is important, that throughout the research process, the language and terminology used are acceptable.
    - Use ‘disabled people’ or ‘persons with disability’. See this note on terminology by the Department of Disability Studies.
    - Do not use abbreviations such as PWD (People with Disability) or PID (People with Intellectual Disability) throughout your dissertation. However, you can refer to a particular profile as an acronym. For example, ‘a person with CP’ (Cerebral Palsy).
    - Use ‘wheelchair-user’ not ‘wheelchair-case’ or ‘wheelchair-bound’.
    - Do not use ‘people with special needs’.
    - Do not use negative terms such as ‘suffers from’: for example, say ‘John has cerebral palsy’ not ‘John suffers from cerebral palsy’.
    - Do not equate the person with their condition; for example say ‘Mary has Down syndrome’ not ‘Mary is Down syndrome’.
    - For further guidance see the *Rights Not Charity* of the Commission for the Rights of Persons with Disability .
2. Questions which are of a personal nature: do not ask for personal details unless they are directly relevant to your research. If you need to ask for such details, do so with sensitivity and do not press further if the person feels uncomfortable.

3. Ensuring research participants' confidentiality of personal data: use pseudonyms for your research participants, and ensure you do not disclose any personal data unnecessarily. Participants may still be identifiable in spite of all effort to pseudonymise the data. In such situations, you would need to include this point in the information letter and consent form, as well as possibly fictionalising the personal data. For example, using 'wheelchair-user' instead of a person with cerebral palsy. However, one needs to be careful that some fictionalisation does not impact the research agenda and aims. Alternatively, the participants may choose to be identified, and therefore, the consent form should reflect this.

4. Obtaining informed consent: when obtaining consent from disabled participants, ensure that all documents are produced in accessible formats (see points A 5 and 6 above).

    - If the participants have an intellectual disability and are over the age of 18, it should be presumed that they can give informed consent (using easy-to-read documents). It is only if a participant has had their legal capacity rights removed (through interdiction, incapacitation, or a guardianship order which covers giving consent to research), that formal consent needs to be provided by their curator or guardian. Consent should still be

obtained from the disabled person. If they do not want to take part, this wish should be respected, even if the legal representative has given consent.

- If the participants are disabled children and young people below the age of 18, formal consent will need to be sought from their parents or legal guardians. However, assent should still be sought from the participant and they should also be given an information sheet and an assent form to sign. These should be presented in an age-appropriate format and should be drawn up on the basis of the individual's cognitive ability. If the prospective participant does not want to take part, their wish should be respected, even if the parent/guardian has given their consent.

5. Disabled people with profound intellectual and multiple disabilities (PIMD): it can be very difficult to obtain the views of these disabled persons (although there are specialised ways in which they express themselves). To study the issues that concern disabled people with PIMD, it may be more appropriate to carry out the research with their parents or other primary caregivers.
6. If, as part of your ethical procedure, you are sending the transcript of interviews for research participants to check, make sure that you address any access needs of disabled participants. In the case of participants with cognitive impairment, or with any other difficulties in reading and/or understanding the transcripts, you should meet with them to go through the transcript together.

7. Observe the rules of disability etiquette when interacting with disabled persons. See Chapter 3 of the Guidelines for Employers published by the Commission for the Rights of Persons with Disability.

C. Thinking and Writing about Disability

The following points will help you take disabled people's perspectives into account when formulating your research question and the research tools, as well as when you are analysing the data generated from your research:

1. Disabling barriers: think of how disabled people's experiences arise from physical and cultural disabling barriers, not simply from physical or mental limitations.

2. Positive and negative: do not assume that the experiences of disabled people and of their family members are always negative. Disabled people's experiences are just like the experiences of any minority group and people in general. Be open to examples of good practice; factors that promote inclusion and access for disabled persons; and positive experiences.

3. The diversity of disabled people: do not see disabled people's views and experiences solely in terms of their disability. Consider the intersectionality of their identity (such as their gender, their sexual orientation; their socioeconomic, cultural and family backgrounds; and their different personal experiences and personalities). Consider the intersectionality of these issues in your research, especially when analysing the data.

4. Disabled people’s expertise: disabled people are experts in their own lives. Those closely associated with them, especially parents, also have expert knowledge of disabled people's lives from the point of view of carers.

5. Dissemination of research findings: should your dissertation be made available in the library, contribute to improving disabled people’s lives by disseminating your research findings as widely as possible. Send a summary of your findings (in an appropriately accessible format) to disabled research participants and the organisation or institution through which you recruited them.

Consultation for Students' Research

Students who carry out research with disabled people for their dissertation should be provided with guidance regarding the ethical issues outlined above throughout the research process. If the main supervisor's areas of expertise do not include disability studies, the Department of Disability Studies can provide advice. Please write to disabilitystudies.fsw@um.edu.mt.

Prepared by the Department of Disability Studies, Faculty for Social Wellbeing, University of Malta

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