Ethical Guidelines for Carrying Out Research with Disabled People

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http://www.um.edu.mt/socialwellbeing/disabilitystudies

Note: The University Research Ethics Committee already provides detailed ethical guidelines for conducting research with human subjects. These can be downloaded from: https://www.um.edu.mt/urec.

The present document complements these guidelines by providing further guidance regarding ethical issues in doing research which involves interaction with disabled people.

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

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[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. Available at: 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 page numbers]

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, and any of the participants have reduced mobility, ensure that the venue chosen is accessible to all, unless it has been chosen by the disabled persons themselves. KNPD's Access for All Guidelines provide details about physical accessibility (http://crpd.org.mt/wp-content/uploads/2016/04/Access-for-all-2005.pdf.) 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 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 is going to take long, there are accessible sanitary facilities nearby.

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 own 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 own car, make sure that there are reserved parking bays for disabled people close to the venue.

3. 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 person uses Maltese Sign Language, you will need to make arrangements (including payments) for a sign language interpreter.
    - If the person relies on lip reading, make sure that the venue is well lit and that there is no bright light directly in your face.
    - If the person uses an assistive listening device, take time to learn how they use it.

4. Use of communication aids: if the disabled person uses a communication aid, an assistive or 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.

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

- This document is written in a sans serif font, size 14, 1.5 line spacing and with no right margin justification – this makes it more accessible for people with print disabilities (such as people with visual impairments, and people with specific learning difficulties).
- Child-friendly versions should be produced if disabled children are involved as research participants. The Child Rights International Network has produced guidelines on producing child friendly documents. See https://www.crin.org/en/library/publications/crc-guidelines-child-participation-crc-reporting.
- People with intellectual disability need printed information to be available in easy-to-read formats. MENCAP has produced guidelines on how to write in this format. These are available from https://disabilitystudies.nl/sites/disabilitystudies.nl/files/making-myself-clear.pdf.

6. Access to online material: the points outlined in A5 above are also relevant if you are sending out material electronically. Furthermore, 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. If you are using an online survey it is important to ensure that it is accessible for people with visual impairment. Online questionnaires in general are accessible, but some question formats, such as the grid in Google Forms, are not. For an example of an accessible questionnaire see: fitamalta.eu/survey. For further information about IT accessibility, you can see the resources on the FITA website or contact them directly for further guidance: http://www.fitamalta.eu/.

7. Disabled persons may have other impairment-related requirements which are not mentioned in the points above. Make sure 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’.
    - Do not use abbreviations such as PWD or people with ID.
    - 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 *Drittijiet Mhux Karità* (Rights Not Charity) guidelines, available from http://www.knpd.org/awareness.html.

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: use pseudonyms for your research participants, and make sure you do not disclose any personal data unnecessarily. If the disabled person is frequently in the media, they may still be identifiable. In that case ask the person if s/he minds if a reader might identify them.

4. Obtaining informed consent: when obtaining consent from disabled participants, make sure that information sheets and consent forms 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 have the capacity to give informed consent (using easy-to-read documents). If a participant has had their legal capacity rights removed (through interdiction, incapacitation, or a guardianship order which covers giving consent to research), formal consent needs to be given by their curator or guardian. Consent should still be obtained from the disabled person and if s/he does not want to take part, this wish should be respected, even if the legal representative has given consent.
   - If the participants are disabled children (i.e. 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 child and they should also be given an information sheet and an assent form to sign. These should be in an age-appropriate child-friendly format and should be drawn up on the basis of the individual's cognitive ability. If the child does not want to take part, his/her wish should be respected, even if the parent/guardian has given his/her consent.

5. Disabled people with profound and complex dependency needs: it can be very difficult to obtain the views of these disabled persons (although there

are specialised ways in which they express themselves). In order to study the issues that concern disabled people with profound and complex dependency needs, it may be more appropriate to carry out the research with their parents or other primary caregivers.

C. Thinking and Writing about Disability

The following points will help you take disabled people’s perspectives into account when you are 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: don’t assume that the experiences of disabled people and of their family members are always negative, just like the experiences of any minority group. 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: don't see disabled people's views and experiences solely in terms of their disability. They are also male, female or transgender; have different sexual orientations; come from different socioeconomic, cultural and family backgrounds; and have 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: if your dissertation is being made available in the library, give a contribution 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

It is recommended that students who carry out research with disabled people for their dissertation are 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.