Transition towards Independent Living Within the Community EU-Arab Cooperation Forum on the Rights of Persons with Disabilities

14-15 February 2023

Workshop on Disability Research for Early Career Researchers

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Applying the Social Model of Disability to Research

Examples of focus medical aspect

- Assessing difficulties in walking
- Evaluating impact of hearing impairment on a person's ability to communicate
- Measuring prevalence of different types and level of visual impairment
- Testing functional abilities of persons with cognitive impairment
- Assessing effects of different drugs and therapies on mental illnesses

Examples of focus on the social aspect

- Assessing difficulties created through lack of ramps, lifts and other aspects of physical accessibility
- Evaluating impact of lack of subtitling and of sign language interpretation on the inclusion of persons with hearing impairment
- Measuring prevalence of use of accessible documentation for persons with visual impairment
- Testing the effectiveness of different support interventions to enable the full development of persons with cognitive impairment
- Assessing the effect of stigma on persons with mental illness

A Social Relational Perspective

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UNCRPD Preamble para (e))

Research on:

- the effect of impairments
- social factors which enable participation and inclusion
- social factors which create barriers and hindrances

Whose Perspectives Count in Disability Research?

 The primary importance of the experiences and perspectives of disabled people and their family members

Different types of expertise and knowledge: professional and experiential

The origins of emancipatory disability research: Miller and Gwynne's research in the late 1960s and the response from Paul Hunt
 (https://tonybaldwinson.files.wordpress.com/2018/04/settling-accounts-with-the-parasite-people-a-critique-of-a-life-apart-by-ej-miller-and-gy-gwynne-by-paul-hunt-1981.pdf)

The Role of Persons with Disabilities in Research

As:

- sole or main researchers
- co-researchers
- research advisors

In:

- deciding on research question(s)
- designing the research (e.g. methods used, interview questions)
- carrying out the research
- analysing the research data
- writing up the analysis and discussion
- dissemination of research findings

Dissemination of Disability Research

• Articles in scholarly publications - peer-reviewed journals and books

Summaries of main findings in accessible formats - including easy-to-read

 Using research findings as an advocacy tool – with disability activists, decision makers and service providers

Further Reading About Disability Research

- Barnes, Colin (2008) An Ethical Agenda in Disability Research: rhetoric or reality? In Mertens, D. M. and Ginsberg P. E. (eds.) 2008: *The Handbook of Social Research Ethics*, London: Sage, pp. 458 – 473. Prepublication version available from: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-research-ethics-2.pdf
- Stone, E. and 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. https://eprints.whiterose.ac.uk/927/1/priestleym1.pdf
- University of Malta. Ethical Guidelines for Carrying Out Research with Disabled People.

https://www.um.edu.mt/media/um/docs/research/urec/DisabilityGuidelines.pdf

Potential Research Project

In groups, formulate a research question about independent living in the community keeping the following points in mind:

- What is meant by 'independent living in the community'?
- What do you think are the main concerns of disabled people that you should focus on?
- How will disabled people participate in the research?
- Who else will be involved in the research?
- How will research results be disseminated?

Writing a Research Article

- Adapting material from dissertation research (especially postgraduate)
- Writing up results from a research project
- Discussion of research findings
- For large scale projects: different articles focusing on different aspects of the research
- Discussion of methods used, especially regarding involvement of disabled people
- Brief background and literature review (including country background if relevant)
- Brief description of methodology, including ethical procedure and method of data analysis
- Presentation of results analysis
- In-depth discussion of results
- Limitations
- Conclusion

The Review Process

- Check submission guidelines for the specific journal you are submitting to
- Draft article is sent out for review to at least two reviewers (usually anonymously)
- Article is rejected/sent back for major amendments/accepted with minor amendments
- If rejected, take note of the feedback, revise the article accordingly and submit to another journal
- If sent back for major amendments, make the necessary changes. Also attach
 a document to list changes made. If there are any suggestions from the
 reviewers that you don't agree with, explain why you did not take these
 suggestions on board

Main Disability Research Journals (in English)

- African Journal of Disability: https://ajod.org/index.php/ajod (open access)
- Alter European Journal of Disability Research (English and French) https://journals.openedition.org/alterjdr/268
- Canadian Journal of Disability Studies (English and French)
 https://cjds.uwaterloo.ca/index.php/cjds/about (open access)
- Disability & Society (includes open access Breakthrough Scholar and Current Issues sections)
 https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=cdso20
- International Journal of Disability Research and Social Justice: https://www.plutojournals.com/international-journal-of-disability-and-social-justice/ (open access)
- Scandinavian Journal of Disability Research: https://www.sjdr.se (open access)

POINTS FOR ATTENTION

- Calls for articles for special issues of journals / calls for book chapters
- Check journal's international standing:
- ✓ Peer-review process
- ✓ Impact factor
- ✓ Indexing
- ✓ Editorial board

• Be careful with unsolicited invitations to publish journal articles or books; vanity publishing.

Free Open Access Sources of Information

- Academia.edu: https://www.academia.edu
- Researchgate: https://www.researchgate.net
- British Library Doctoral Theses Database:
 https://ethos.bl.uk/Home.do;jsessionid=7E9E09ED843DE811123B1A0C08060
 B38
- Open Access Repositories of various universities
- University of Leeds Disability Archive https://disability-studies.leeds.ac.uk/library/authors/B/
- University of Leeds Disability-Research Discussion List: https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=disability-research
- University of Maryland DS-HUM Discussion List: https://listserv.umd.edu/cgi-bin/wa?A0=DS-HUM

Main Points on Disability Research